Cross-Border Patient Mobility in Selected EU Regions

Final Report

Prepared by the Association of European Border Regions (AEBR/AGEG)

for

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Table of Contents

Glossary of Terms, Abbreviations, and Acronyms Used in this Report

Term/Abb/Acronym	Full Term or Description
Active Subsidiarity	The term identified in study conclusions to denote the processes where Member States, Subnational, and Regional actors work together to deliver meaningful outcomes for their citizens; this has particular significance as a principle for cross-border territorial cooperation with the EU citizen at its centre.
AEBR	Association of European Border Regions
ARS(s)	Agence(s) Régionale(s) de Santé (regional agencies of national health administration, France)
AOK	German Health Insurer
CESCI	Central European Service for Cross-Border Initiatives
CZ	Dutch Health Insurer
DG SANTE	European Commission Directorate-General for Health and Food Safety (commissioner of this report)
DG REGIO	European Commission Directorate-General for Regional and Urban Policy
DG IPOL	European Commission Directorate-General for Internal Policies of the Union
Data Collaborative(s)	This term is used in the Study recommendations. It denotes multilevel, multistakeholder collaborative initiatives aimed at codesigning mechanisms in border regions to support future data collection on cross-border patient mobility- for the purposes of reporting on the Directive and the Regulations and which can support other forms of cross-border cooperation in health and patient mobility.
EC	European Commission
ECBM	European Cross-Border Mechanism
EDF	European Disability Forum
EGTC	European Grouping of Territorial Cooperation
EHIC	European Health Insurance Card
EPECS	European Patients Empowerment for Customised Solutions (NGO based in Meuse Rhein Region working on EU citizens'

	mobility rights with a special focus on cross-border patient mobility)
ERDF	European Regional Development Fund
EU	European Union
EUPrevent	Regional cross-border initiative in Meuse Rhein Region focusing on socio-economic population needs and outcomes including health and cross-border patient mobility
Euroregion	Organized group of local and regional authorities across a border within public or private law
EHDS	European Health Data Space
EMR	Euregio Meuse Rhein
ERNs	European Reference Networks
GDPR	General Data Protection Regulation
Healthacross	Cross-border regional health cooperation organisation based in Lower Austria facilitating cross-border patient care with Czechia and Slovakia
INTERREG	EU Programme supporting cross-border, transnational, and interregional development and cooperation, drawn from the European Regional Development Fund, and implemented by DG REGIO
IZOM	Integratie Zorg Op Maat- pre-Directive bilateral health insurance arrangement - Meuse Rhine Region. Involved Dutch insurer CZ, Belgian insurer Mutualité Chrêtienne and German insurer AOK.
MOT	Mission Opérationnelle Transfrontalière
NFZ	Polish National Health Fund
NCP(s)	National Contact Point(s)
OBR	Ostbelgien Regelung- cross-border patient mobility agreement supporting the German-speaking community of East Belgium in accessing cross-border healthcare
OFBS	French-Belgium Health Observatory
REGI Committee	The European Parliament's Committee on Regional Development

The Directive	DIRECTIVE 2011/24/EU OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 9 March 2011 on the application of patients' rights in cross-border healthcare
The Regulations	The Social Security Regulations of the European Parliament and of the Council: Regulation (EC) No 883/2004 of 29 April 2004 on the coordination of social security systems; and Regulation (EC) No 987/2009 of 16 September 2009 laying down the procedure for implementing Regulation (EC) No 883/2004
TRISAN	Centre de compétences trinational pour vos projets de santé
ZOAST(S)	Zone(s) organisée(s) d'accès aux soins de santé transfrontaliers (bilateral healthcare cooperation arrangements within Grande Region originating between Belgian and French healthcare and insurance providers and pre-dating the Directive)

Executive Summary

Article 20 of the EU Directive on the Rights of Patients in Cross-border Healthcare places a legal requirement on Member States to report data to the European Commission for the purpose of monitoring cross-border patient mobility. This study was commissioned by the Directorate-General for Health and Food Safety (DG SANTE) and carried out by the Association of European Border Regions.

Aim and Objectives of the Study:

The overall aim of the project was to provide an overview of cross-border patient mobility and the reimbursement system used for planned healthcare treatment in a number of selected border regions and between neighbouring Member States, in order to complement (with qualitative and -where available- quantitative data), the data on cross-border healthcare collected for the purposes of Directive 2011/24/EU and the Social Security Coordination Regulations 883/2004 and 987/2009.

The specific objectives of the study, in consideration of the aim and purpose above, were to carry out four case studies of patient flows between EU border regions and in doing so to:

a) gather available data on cross-border patient flows in the case study regions/patient pathways using different reimbursement mechanisms for planned healthcare (Directive, Social Security Coordination Regulations, and other bi-lateral arrangements);

b) gather qualitative information, where available and feasible, on the types of treatment for which patients seek cross-border healthcare or information on patient mobility within the context of COVID-19 (COVID-19 and non-COVID-19 patients) and of communication on cohesion in border regions;

c) improve understanding of the methodological difficulties involved in monitoring patient flows, to collect data on the different reimbursement mechanisms;

d) provide recommendations to improve data collection on patient mobility at EU-level for the purpose of Directive 2011/24/EU (reporting requirements under article 20) and actions which could be taken at regional, national and EU-level.

The 4 case studies respectively focused on:

1. Meuse Rhein region (Germany/Belgium/ Netherlands)
2. Grand Est region of France (FR)-Luxembourg,
3. Lower Austria/Bohemia/Slovakia (Austria/Czechia/Slovakia), and
4. General patient flow between Poland and Czechia as neighbouring countries.

Project Team:

The project team comprised practitioners with policy expertise in cross-border collaboration and healthcare collaboration, and EU health data/related health data law. AEBR Project team members were Martin Guillermo Ramirez (AEBR Secretary-General), Caitriona Mullan (Study co-ordinator and AEBR Expert in cross-border collaboration practice and policy), Petra Wilson (AEBR study associate and health data expert), and Martina Mollering (AEBR project support officer).

Methodology:

The study methodology consisted of 4 key strands for each case study? which translated into detailed workstreams. In terms of implementation, workstreams overlapped with each other and were interdependent- the management of these workstreams was undertaken reflexively, allowing for the highest possible level of coherency at each stage of inquiry, analysis, and in the drawing of conclusions from the case studies and from the project overall.

Workstreams 1 and 2 focused on qualitative and quantitative data collection. This workstream involved a literature review, a review of existing data baseline information, stakeholder mapping and establishment of a respondent pool (over 200 respondents), a research protocol design (covering consent and privacy notices, survey questionnaire, and questions for interview, and implementation of an initial survey questionnaire which mapped potential sources of complementary data. Further data discovery and data mining analysis followed, as did over 40 semi-structured interviews (including group interviews) with a wide range of respondents including health insurers, healthcare providers (including clinicians providing cross-border care), patient representative/advocacy organisations, third level research organisations, cross-border healthcare organisations and cross-border regional civic organisations (including Euregio structures). Focus groups were also held for each of the case study areas.

Workstream 3 involved the testing and validation of findings- at initial stage through the presentation of early research findings at focus groups in the case study regions, and at a later stage with a formal results validation webinar held online on 6th October 2021 and an additional results feedback workshop which AEBR conducted as part of its annual conference in 2021, involving the AEBR Task Force on Cross-border Healthcare. Additional validation took place on an individual basis with key research respondents on specific contributions to various components of the study and in particular where quantitative data was provided for the purposes of the study.

Workstream 4 involved the development of recommendations which was underpinned by discussions at focus groups in the mid-stage of the study initially. These recommendations were further refined in the context of emerging findings and tested again at the validation events referred to above, which took place during the month of October.

Key Findings and Conclusions of the Study:

The study presented specific findings in relation to geographical case study areas which

focus on how patient mobility data is collected currently and how it might be useful in the future. The study also presented case study findings reflecting the qualitative conditions and future potential for cross-border patient mobility in the case study regions. In acknowledging that all case study regions revealed a level of capacity for institutional cross border collaboration to support patient mobility (on both practical measures and research/data related activities) and that future data collection approaches should involve subnational and regional actors in multistakeholder collaborative initiatives, the study reached a number of key conclusions, as follows:

The COVID-19 pandemic highlighted the importance of good quality data in the effective functioning of healthcare systems both domestically and across borders (where urgent patient transfers were concerned). It is a policy priority of the EU to ensure that the Union has well-functioning and effective healthcare systems. A core feature of these must be good data that allows for the monitoring and improvement of healthcare systems.

While data on cross-border patient mobility is a small subset of overall healthcare data, it underpins an important legal commitment of all Member States and the EU to monitor the extent to which the Directive supports patient rights in cross-border healthcare.

Member States/NCPs need to develop complementary mechanisms for collecting data on patient mobility which is of sufficient detail to support monitoring of the Directive and also the Regulations, and which can better inform improvements in the planning or quality of cross-border and in-country healthcare.

The Commission's annual report on patient mobility data concludes that most National Contact Points for cross-border healthcare (NCP) either collect or are able to access good data which differentiates between different reimbursement mechanisms including the Social Security Regulations and the Directive. However, differentiated data is not consistently the case nor do all Member States provide the data- in fact some Member States report no data at all. Overall there is a lack of robust data to adequately report on patient mobility in the EU.

Where NCPS have been unable to collect data that clearly differentiates between reimbursement mechanisms, the case studies have shown that in some regions insurers and cross-border healthcare delivery and/or health promotion organisations do collect data which provides this information. In some countries, arrangements are in place with umbrella organisations in the health insurance sector to ensure that this data is shared with the NCP for purposes of reporting to the European Commission on the Regulations and the Directive.

Article 20 of the Directive sets a legal requirement for Member States to report available data which enables monitoring of the Directive on the rights of patients in cross-border healthcare; the findings from the case studies suggest that data is available and could be collected by insurers and regional bodies for the purposes of the reports made annually to the European Commission by Member States via the NCPs if legal barriers are overcome and administrative mechanisms put in place.

Data capture design and collection needs to be based on best practice approaches to data collection; it needs to be a collaborative process involving Member States, NCPs,

and relevant stakeholders in healthcare provision, healthcare insurance, and in regional cross-border collaboration.

There is insufficient data on the use of the Directive among Member States. For example, it is not possible to determine the types of healthcare nor the degree to which specific patient groups such as patients with rare diseases are accessing cross-border healthcare or ease of access for people with disabilities who often encounter additional barriers to equality of health outcomes. Better understanding is required of how the application of the Directive and also the Regulations can better benefit all patients with a wide range of needs and better data could help identify and resolve potential barriers to equality of access.

Border regions are recognised by the European Commission as important laboratories for European Integration and as such may serve to pilot improved approaches to cross-border patient mobility data. They are also key drivers of data-driven territorial cooperation and spatial planning. Civic organisations in border regions are useful partners for Member States and health sector stakeholders in addressing the challenges of cross-border patient mobility data and are experienced in facilitating the kind of collaborative approach that this study recommends.

Main Recommendations of the Study:

The study has made 9 recommendations based on a full analysis of all qualitative and quantitative findings on data collection and the wider conditions for patient mobility in the case study regions in which data collection is located and which are a key influencing factor for cross-border patient mobility. Recommendations relate to patient mobility data collection and conditions for cross-border patient mobility, and secondly, to the role of border regions as laboratories for innovative collaboration in healthcare. The final chapter of the report identifies the stakeholders who need to be involved in implementation at multiple levels- EU, Member State, subnational, and regional cross-border.

Improving Patient Data Collection

1. Member states should work with health insurers and all other relevant data owners (including healthcare providers and cross-border organisations) to develop in-country mechanisms to ensure that better data is available and reported to the European Commission on cross-border patient mobility as required by the Directive on patients' rights in cross-border healthcare, as follows:

   Data collection mechanisms should be improved to ensure that data collected on cross-border care includes information on types of treatment accessed, and can differentiate between different reimbursement tools used, including local and regional tools.

   Data collection tools should be expanded to include demographic data on patients as well as categories of care accessed (ideally by clinical classification) to allow for fuller assessments of use and needs to be made.

   Data collection mechanisms should be developed on a multilevel basis with a

range of partners in cross-border regions, allowing neighbouring NCPs to coordinate and reduce duplication of effort and resources.

2. Member States should be encouraged to establish pilot collaborative data design and collection initiatives in border regions- pilots could be EU funded initially. Pilot initiatives should include:

a) Mapping and testing regional/sectoral capabilities for providing more detailed data on patient mobility for the reporting period covering 2021-23;
b) Co-designing schematic approaches to future data collection on patient mobility which include specific data on use of the Regulation, the Directive, and other reimbursement mechanisms; using an action-research approach;
c) Exploring how additional cooperation on patient mobility data can support collaborative approaches on cross-border healthcare that are aligned with population health needs. Using patient journey mapping as a tool in this process;
d) Exploring how integration of health and patient mobility data with regional spatial planning evidence (e.g. Smart Regions, Smart Cities, ESPON network projects), European Digital Innovation Hubs) can lever added benefits for future data collection on patient mobility AND contribute to smart and resilient regions.

3. The development of the EU Health Data Space should include exploration of how interoperability of patient data systems can also support the collection of statistical data on cross-border patient mobility.

Strengthening cross-border regional cooperation in healthcare

4. Technical support and resources should be provided for key border regions including the case study regions, to explore options and facilitate solutions for more structural regional cross-border healthcare cooperations which are based on complementarity, critical mass and cross-border patient catchment populations. These should include:

a) joint-commissioning of high-cost clinical capital equipment;
b) specialty services development on cross border patient catchment/population health needs models;
c) general hospital/primary care collaboration in border areas; and
d) development of advocacy actions focused on the role of functional cross-border health regions in contributing to national excellence and improvement in healthcare.

5. Further exploration should take place in border regions of approaches to clinical care provision which are based on evidence of population health needs in border areas (as a basis for coordinated shared services and also clinical innovation in patient care, including integrated care models).

6. NCPs should liaise with stakeholders in border regions to determine if there may be collaborative approaches to:

a) Improving awareness and availability of information to all patients through a variety of approaches and outreach at local level as well as information on NCP websites; and

b) Improving access to information for patients with disabilities and for patients with rare diseases and their families/carers.

7. Where baseline information does not exist for patients who want to access cross-border care, and where there may be cross-border socio-economic discrepancies between Member State of residence and Member State in which care is being sought, the European Commission and the wider EU community of research institutions and programmes should explore ways to support baseline work to create patient information (e.g. pricing structures) and capacity building in key border regions.

8. Using innovative cross-border collaboration between neighbouring countries and in border regions, Member States should:

    a) Explore the role of the Directive in addressing the demand for planned care throughout the EU, and in border regions, arising from the Covid-19 Pandemic; and
    b) Develop shared protocols between Member States for cross-border patient mobility and frontier worker mobility based on learning from the Covid-19 pandemic and in interests of keeping patient pathways open and guaranteeing the healthcare workforce mobility required for health services to operate to their full capacity with safe levels of staffing.

9. The findings of this study should be followed up and taken forward with key actors within the European Commission and Member States. This process should also involve stakeholders in the field of EU regional and cross-border policy, cross-border co-operation and health.

Introduction

This project was contracted by the European Commission under the Health Programme 2014-2020. The overall aim of the project has been to provide an overview of cross-border patient mobility and the reimbursement system used for planned healthcare treatment in a number of selected border regions and between neighbouring EU Member States, in order to complement (with qualitative - and where available- quantitative data), the data on cross-border healthcare collected for the purposes of Directive 2011/24/EU.

The specific objectives of the study were as follows:

To carry out four case studies of patient flows between EU border regions to:

1. gather available data on cross-border patient flows in the case study regions/patient pathways using different reimbursement mechanisms for planned healthcare (Directive, Social Security Coordination Regulations, and other bi-lateral arrangements);

2. gather qualitative information, where available and feasible, on the types of treatment for which patients seek cross-border healthcare or information on patient mobility within the context of COVID-19 (COVID-19 and non-COVID-19 patients) and of communication on cohesion in border regions;

3. improve understanding of the methodological difficulties involved in monitoring patient flows, to collect data on the different reimbursement mechanisms;

4. provide recommendations to improve data collection on patient mobility at EU-level for the purpose of Directive 2011/24/EU (reporting requirements under article 20) and actions which could be taken at regional, national and EU-level.

The report makes both case-specific and overarching recommendations for further consideration by the European Commission and a range of national, subnational, and regional actors whose involvement will be essential to the development of future approaches to data collection on patient mobility.

1.0 Chapter 1- Project Context, Brief, and Approach

Planned Healthcare Treatment in another EU Member State

Most patients prefer to receive healthcare at home close to their families. Access to cross-border healthcare is important for certain groups of patients with a specific health condition and in situations where the most appropriate treatment or the nearest hospital is in another EU country. EU legislation provides citizens with three ways to access healthcare in another Member State and be reimbursed for the treatment costs:

i. unplanned treatment healthcare based on the European Health Insurance Card (Regulation (EC) No 883/2004 and Regulation (EC) No 987/2009)
ii. planned healthcare based on Regulation (EC) No 883/2004 and Regulation (EC) No 987/2009 ("the Regulations") and
iii. planned and unplanned healthcare based on Directive 2011/24/EU on the application of patient rights in the EU ("the Directive")[1]

The Directive clarifies the rights to cross-border healthcare stemming from the case-law of the European Court of Justice and complements the separate EU Regulations on social security coordination thus offering more possibilities for patients to seek planned healthcare abroad. As a result, EU citizens have more choices: either to seek medical care at home or, according to their situation, in another EU country. They can claim reimbursement from their national health system or insurance provider. In addition, a number of parallel procedures exist to address the healthcare needs of people living in European border regions. In some Member States, these account for much more significant cross-border patient flows than the Directive or Regulations. However, there is no obligation on authorities to report on the operation of these parallel schemes to the European Commission, except where such schemes have benefited from special EU funding mechanisms (such as the INTERREG Programme). As a result, it is not possible to include the flow of patients under many of these schemes in the assessment of patient mobility across European borders.

Patient Mobility in the EU- Implementation of the Directive

The Directive was adopted in 2011 to codify the rights of European citizens to receive care in a Member State other than the State in which they are insured and usually reside. It sets out in EU legislation the rights established 1998 by the European Court of Justice the joined cases of Kohll/Decker 1, which provided that no prior authorisation is required for planned outpatient care in another Member State (Kohll) and that no prior authorisation is required for the purchase of medical devices or medical products on prescription (Decker) in another Member State.

[1]DIRECTIVE 2011/24/EU OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 9 March 2011 on the application of patients' rights in cross-border healthcare

This was followed by further cases - Geraets-Smits v Stichting Ziekenfonds VGZ and Peerbooms v Stichting CZ Groep Zorgverzekeringen 2, which clarified that Member States have the right to determine the scope of implementation of their health systems, the rules on the freedom of goods and services must respect each Member State's freedom to organise their healthcare system. Moreover, the Directive applies generally without any form of prior agreement from the insurance funding body in the country of affiliation but also allows Member States to adopt rules that require patients to seek prior authorisation under certain conditions and for certain types of treatment.

Reporting on the Directive

Since its entry into force in 2013, the National Contact Points (NCPs) have reported three broad categories of data on the use of the Directive each year: requests for information, requests for prior authorisations, and reimbursements claims for care provided in another country where no prior authorisation was sought. These reports are made in accordance with the requirements of Article 20 of the Directive which specifies that the European Commission shall draw up a report on the operation of the Directive to be submitted to the European Council and Parliament every three years. The NCPs report both data that they collect themselves and data they receive from the insurance providers in their countries. In some countries, the NCPs are able to report only very limited data, and in some cases, they can report no data at all because there are no national arrangements for this data to be shared or collected and in other cases, there is no domestic legal basis for the NCP to obtain the data. The result is that the official data available on the use of the Cross-border Care Directive (drawn from 20 countries) do not provide a complete picture of patient mobility.

In addition to the Directive, the Regulations also cover patients receiving planned care in a Member State other than the one which provides their statutory healthcare insurance however prior authorisation is always required. As well as covering planned care, the Regulations also cover reimbursement for unplanned healthcare which becomes necessary during a temporary stay in another Member State (usually through the use of the European Health Insurance Card -EHIC) and healthcare provided to pensioners living abroad and frontier workers who work in one Member State but reside in another.

With regard to data collected from Member States under the Regulations, the Commission has also reported that data from some countries are not complete, and in some cases not available at all.

According to DG SANTÉ's 2020 report on patient flows in 2019, some 250,000 reimbursements for cross-border care were made. Some of these may have been for the same patient, so the number does not necessarily reflect the number of patients who travelled to another country for care. The majority of patient flows are between neighbouring countries sharing borders, more detail on the numbers of patients travelling are given in section 1.2.2 below.

Cross-border healthcare under the Directive is assumed to be particularly important in border regions where people cross borders every day to work and where they share language.

Limited evidence suggests that bilateral agreements between neighbouring health authorities or hospitals in border areas also influence patient flows as do the existence of parallel procedures under the national legislation for planned healthcare abroad. Where figures are available for these parallel schemes, patient mobility is usually much larger than under the Regulations and the Directive. There is no EU-wide data available on the specific role of local bilaterals in facilitating cross-border patient flow.

In the Benelux region, a report on patient mobility from 2013-2016[2] contributed to a broad understanding of patient mobility along the borders of BE, NL, and LU. This report, while it referred to data from a specific time period, nevertheless contains much that continues to be relevant for the organisation of cross-border care and patient mobility and was an important collaborative policy initiative involving the Benelux countries acting in recognition of the importance of cross-border patient mobility and healthcare for the populations and economies of the Benelux countries. It highlighted the potential for case studies on patient mobility in border regions to create a better understanding of specific flows. While these data collection efforts provide a broad understanding of patient mobility in the EU, the information remains incomplete and inconsistent with data lacking from important Member States and no data available on the types of treatment patients receive. Recommendations from the European Parliament have called for improved information on patient flows.

The Commission is working with Member State representatives in the Cross-Border Healthcare Expert Group and the National Contact Points to improve the information collected on patient mobility under the Directive as data is still lacking or incomplete. These national experts were consulted as part of this study.

The Directive encourages Member States to facilitate cooperation in cross-border healthcare provision at regional and local level, including border regions. The latter is an important opportunity to improve access to care for patients, to capitalise on economies of scale, and to use resources efficiently.

The EU supports cooperation and integration of health systems in border regions with its Interreg programmes. For example, there are seven zones of organised access to cross-border healthcare have been created alongside the Franco-Belgian border; emergency control centres of Lower Austria, South Bohemia and South Moravia are linked in real-time to enable Cross-border healthcare in the EU. In Upper Rhine between the French-Germany-Switzerland border, the TRISAN project coordinates networking activities in the healthcare sector. The Euregio Meuse-Rhine in the Maastricht-Aachen-Liege-Hasselt has established a long-term cooperation to collect, analyse and compare existing data and to make these data available through the project „towards cross-border health data for the EMR“ which started in 2017. The case studies within this research project include a focus on these specific initiatives in selected cross-border regions.

[2] General Secretariat of the Benelux Union (2016): *Patients without Borders- Cross-border Patient Flows in the Benelux;* (Auth: Karen Jutten in cooperation with Peter Janssens); this is referenced further in case studies 3A (Meuse Rhein) and 3B (Grand Est).

In its Communication on Boosting Growth and Cohesion in EU Border Regions[3], the Commission showcases a number of successful practices promoting the pooling of services along internal borders including healthcare. However, evidence gathered by the Association of European Border Regions as part of the *b-solutions* project identifies obstacles in border regions due to a lack of regional, cross-border solutions in complex healthcare services payment procedures, which can significantly affect the well-being of people living in border regions[4]. The Regional Hubs Network of the European Committee of Regions is a platform, which aims to involve key local and regional actors through effective consultations in order to collect their experiences on EU policy implementation. The RegHub Network recently carried out a consultation on how well the cross-border healthcare directive has been taken up by regional authorities in the EU. The RegHubs report that while the experience of data gathering and monitoring patient flows is usually a task for national authorities, it is of interest – financially and in terms of planning matters – for regions to know how many patients seek healthcare in their region or go to another healthcare provider for their treatment.

1.1 Scope of the Study

The study has focused on available data on patient mobility patterns, institutional/cross-border cooperation arrangements, and associated issues for cross-border mobility in relation to 4 case studies, grouped as follows:

- Case studies 1, 2 and 3: specific identified cross-border regions in countries where there is evidence from the Commission's annual report on patient mobility data of use of the Directive as the vehicle for facilitating cross-border healthcare access and provision for citizens, and reimbursement of patients or healthcare insurers (even if only partial) for the costs of care.
- Case study 4: patient mobility between neighbouring countries drawing on Poland/Czechia as a case example.

Within this, the study's scope also related to any data and qualitative information pertaining to cross-border patient mobility and in particular the implementation of the Directive in the case study regions or between neighbouring countries.

The study's scope has not only covered quantitative data available at Member State and regional level (where available) but also qualitative information which has arisen during the course of inquiry with stakeholders.

For case studies 1, 2, and 3, the geographical scope of the study was the following regions:

- Meuse-Rhine region: Germany, Belgium, Netherlands;

[3] European Commission (2017): *COMMUNICATION FROM THE COMMISSION TO THE COUNCIL AND THE EUROPEAN PARLIAMENT Boosting growth and cohesion in EU border regions.*

[4] European Commission & Association of European Border Regions (2020): *b-solutions: Solving Border Obstacles A Compendium of 43 Cases.*

- Grand-Est (France) - Luxembourg;
- Lower Austria/South Bohemia/Slovakia region: Austria, Czechia, and Slovakia;

For case study 4, the geographical scope was primarily key patient flow between Poland and Czechia, but this case study also reflects other findings relevant for data collection and the implementation of the Directive for Czech citizens in border areas, and on specific mobility issues for patients with Rare Diseases.

1.2 General and specific objectives of the study

General Objective of the Study:

The general objective of the study was to provide an overview of cross-border patient mobility and the reimbursement system used for planned healthcare treatment in a number of border regions in order t complement the data on cross-border healthcare collected for the purposes of Directive 2011/24/EU and the Social Security Coordination Regulations 883/2004 and 987/2009.

Specific Objectives of the Study:

The project's specific objectives were as follows:

To carry out four case studies: 3 focusing on patient mobility in specific EU border regions, and 1 focusing on key strands of high patient mobility between neighbouring countries, to:

a) gather available data on cross-border patient flows in the case study regions/patient pathways using different reimbursement mechanisms for planned healthcare (Directive, Social Security Coordination Regulations, and other bi-lateral arrangements);

b) gather qualitative information, where available and feasible, on the types of treatment for which patients seek cross-border healthcare or information on patient mobility within the context of COVID-19 (COVID-19 and non-COVID-19 patients) and of communication on cohesion in border regions;

c) improve understanding of the methodological difficulties involved in monitoring patient flows, to collect data on the different reimbursement mechanisms;

d) provide recommendations to improve data collection on patient mobility at EU-level for the purpose of Directive 2011/24/EU (reporting requirements under article 20) and actions which could be taken at regional, national and EU-level.

1.3 Study Methodology- Summary

This section sets out a summary of the specific methodology by which the study was carried out. In delivering the overall project, AEBR also operated a robust project management model which is detailed in Appendix B (Project Management and Implementation).

The agreed methodology for the study is set out according to the 4 strands of project methodology, associated actions, and limitations/risks and mitigations which were accounted for in terms of fine-tuning and planning during the project inception phase. A detailed version of the methodology is contained in Appendix C; Appendix G contains the original risk analysis of the methodology, developed during the project inception period.

The study methodology consisted of 4 key strands which translated into detailed workstreams. In terms of implementation, workstreams overlapped with each other and were interdependent- the management of these workstreams was undertaken reflexively, allowing for the highest possible level of coherency at each stage of inquiry, analysis, and in the drawing of conclusions from the case studies and from the project overall. This approach was particularly important as findings began to emerge, in particular where outstanding gaps in data -following a detailed data discovery approach- needed to be complemented with qualitative perspectives from each case study.

The Methodology and its Workstreams are summarised as follows:

Workstream 1: Data Collection (Qualitative and Quantitative)

Primary Phase:

- Literature Review
- Existing Data Review and Baseline report
- Stakeholder mapping and establishment of the respondent pool
- Research protocol design (covering consent, initial questionnaire, and questions for interview)
- Implementation of Initial Survey Questionnaire (contained in Appendix C in full). The purpose of this was to identify and map potential sources and nature of data held by stakeholders, for further exploration with stakeholders in the context of interview/focus groups/individual correspondence or a combination of all three. For those who came to be interviewed based on their responses to the survey, the questionnaire return they made also helped to shape the customization of an individual semi-structured interview from a menu of interview questions designed through the Research Protocol.
- Data discovery and mining – this involved detailed and in-depth follow-up with individual stakeholders on sources of data flagged during the inception phase or via initial questionnaire. This was a negotiated process of engagement with individuals who identified sources of data relevant for the study, on the nature of patient mobility and/or to reimbursement of care relating to the case studies. Where data was made available it was analysed by the research team's data expert and processed to inform findings presented at stakeholder focus

groups, and overall findings of each case study.

- Interviews- More than 40 interviews were conducted. Initial interviews were determined following a review of the stakeholder list and information returned as a result of initial information requests during the stakeholder mapping phase. The return of the questionnaire identified additional interviewees, as did signposting by early interview participants to other respondents who were then included in interviewing. In several cases, interviews were group interviews by agreement with respondents, where this was likely to yield better quality of information. Interviewing continued throughout July and August and into September 2021 as this was the optimal method for the research team to confirm their understanding of issues emerging; a number of individuals were also interviewed more than once, at different stages of the research process.
- Consultation Focus Groups. Design of consultation focus groups was based project team's analysis of returns from the initial stakeholder survey, and a review of findings from interviews that had taken place at that point. Consultation focus groups were held in the second half of June 2021, one for each case study.

Workstream 2: Analysis

- Interim analysis was conducted based on issues emerging for each case study area using literature review, questionnaire findings, findings from workshops, and interviews and presented via the interim report.
- Overall Analysis via codified analysis matrix was applied across all four case study areas and has been used to inform case-specific recommendations, and overall conclusions and recommendations.

Workstream 3: Testing and Validation of Findings

- Available qualitative and quantitative data from the initial inquiry phase (literature review, baseline data report and questionnaires) was explored at workshops with stakeholders in the 4 case study regions; findings from the initial inquiry phase and focus groups were further explored at subsequent interviews;
- Emerging findings were peer-reviewed by regional stakeholders, AEBR Task Force on Cross-border Health and shared with NCPs as part of this process

Workstream 4: Drawing of Conclusions

- Webinar on final results on 6th October 2021- this involved peer review of emerging findings from all case study areas, discussion of results, and draft conclusions/recommendations; all those who had contributed to the study through survey response, focus group participation, and interview were invited to participate in the Webinar.
- AEBR Task Force on Cross-border Health- during AEBR's Annual General Assembly and 50th Anniversary Conference held in Arnhem, Netherlands, on 22nd October 2021 AEBR organised an additional special workshop to allow for

members of the AEBR Task Force to provide feedback on results and conclusions/recommendations.

- Incorporating this feedback and findings, AEBR conducted an overall analysis, confirmation of conclusions, and identification of recommendations for further exploration or implementation at the level of individual case study areas and at a general EU level.

1.4 Note on the Study Team and the Association of European Border Regions

AEBR, the organisation providing a commissioned research service to DG SANTÉ for delivery of this project, is a significant NGO with a trans-European reach. AEBR is dedicated to the promotion of cross-border cooperation and supporting all relevant interventions and advocacy actions at European level as well as maintaining cohesion across and between its member regions. In addition to its policy work in partnership with the European Commission and EU policy platforms, AEBR has historically had strong links to the EU institutions by virtue of its member regions, many representatives of whom have been active within the Committee of the Regions and in the European Parliament. AEBR was founded in 1971 with the purpose of promoting cross-border cooperation (CBC). It represents around a hundred border and cross-border regions throughout Europe (members of the Association) and represents indirectly the interests of many more stakeholders. AEBR has been contributing to the establishment of CBC practices for 50 years within and outside the EU, and in other continents.

In recognition of the crucial role of border regions in European Cohesion and Integration, and in delivering equity of outcomes for EU Citizens in border areas, AEBR acts as a strategic advocacy platform for a wide range of policy issues affecting border regions. It also acts as a facilitative platform for the articulation and representation of evidence-based issues for border regions, and this includes direct delivery of services and projects which contribute to a body of knowledge and evidence associated with EU integration issues in border regions.

Since its establishment 50 years ago, AEBR has boosted, promoted, and followed many processes to establish cross-border strategies, programmes, projects, and structures in most European border areas, within and outside the EU, at local, regional, national, and European level, as well as in other supranational integration efforts (African Union, Andean Community, Central American Integration System, Mercosur, etc.) Since the 1970s, AEBR has been directly involved in many initiatives at national, regional, and European levels addressed to establish a more appropriate regulation of territorial cooperation in general, and cross-border in particular, as well as legal frameworks for cooperation between local and regional authorities in Europe, among other regional policy initiatives.

In 1980, AEBR was involved in the preparation and adoption of the Madrid Outline Convention by the Council of Europe; and in the promotion of what it would be called Interreg Initiative in the late 1980s, as well as in Phare CBC, Tacis and IPA related CBC programmes. With the turn of the millennium, it actively promoted a legal instrument for territorial cooperation (later the EGTC, adopted in 2006 and modified in 2013). In

general, AEBR aims to participate in policy dialogues of interest for European border and cross-border regions, such as the Cross-Border Review implemented by the European Commission in 2015-2017 which led to the Communication Boosting growth and cohesion in EU border regions (2017[5]), and many additional outputs. One of these outputs is the *b-solutions* project, to identify legal and administrative obstacles to cross-border cooperation.

In addition to supporting member regions within the European Union, the Association has worked with relevant institutions in the new Member States during the years prior to and after their accession in order to support the implementation of cross-border projects, programmes, and structures.

AEBR also recognises the importance for the EU of cross-border cooperation and cohesion on external borders as a value-adding measure for EU policy, stability, and cohesion objectives. AEBR is active in the area of capacity building and networking on external borders, supported strategically by its Task Force on External Borders. Currently, AEBR, therefore, works with national and regional institutions at the external borders of the EU, including the Russian Federation, Ukraine, Moldova, Western Balkans, Armenia, Turkey, and the Mediterranean basin, following up and supporting CBC development processes in these regions relevant for the EU's external borders.

While it is a membership-based organisation, AEBR also operates according to core principles of friendship across borders and also keeps regular contact with non-member border regions, regional/local development agencies, universities and research centres, experts, and institutions dealing with CBC related issues.

AEBR Task Force on Cross-border Health

Cross-Border Health is an ongoing strategic priority and corporate workstream for AEBR. AEBR recognises that cross-border cooperation on healthcare and public health are key indicators for the wellbeing of citizens and for the principles of cohesion as they apply in border regions. These issues have been highlighted sharply in the context of the COVID-19 pandemic and AEBR has facilitated regular exchanges of information and inter-regional, trans-European dialogue on the impact of COVID-19 and ongoing work to address this in border regions.

In 2007 AEBR established a specific Task Force on Cross-border Health during the AEBR General Assembly in Lappeenranta (South Karelia, Finland). This is composed of representatives and experts from a range of border and cross-border regions, including Euregio Meuse-Rhine and various stakeholders in that region. The Task Force was established mainly to follow up and take part in the process to elaborate the Directive on Cross- Border Health, including exchanges with Commissioners Kyprianou, Vassiliou, and Dalli, with the relevant committees at the European Parliament, and in the initiatives promoted by the European Committee of the Regions.

In the years since the adoption of the Directive, the AEBR Task Force on Cross-border Health has worked regularly on the follow-up of its implementation, especially in

[5] European Commission (2017) *COMMUNICATION FROM THE COMMISSION TO THE COUNCIL AND THE EUROPEAN PARLIAMENT Boosting growth and cohesion in EU border regions* (2017) *regions*, COM(2017) 534 final, 20 September 2017

border regions – and in particular on Directive-related exchange with EU institutions, national, regional, and local authorities. It has participated in specific projects addressing the issue of cross-border healthcare, cooperation, and public health. It has organized various related forums, has taken part in events organized by the EU, and has regular contacts with organizations such as EUREGHA, EPECS (association of patient organisations with founder partner based in the province of Limburg)[6], HOPE, and others working in this field.

The AEBR Task Force on Cross-border Health is a key stakeholder cluster that has been included within the overall stakeholder mapping for this study, which has contributed to the further identification of stakeholders relevant to the research, and through which engagement has enhanced and informed the approach, inquiry, and analysis involved in this research project.

Study Team and Approach:

AEBR carried out its work on this study with an understanding that the brief required an understanding and knowledge of the operational, strategic, and performance data aspects of healthcare service delivery, reimbursement processes, and planning, particularly that relating to cross-border functional areas and patient catchments. AEBR also has a full understanding of the crucial role of information and good quality data on cross-border patient mobility in supporting wider, population-based, strategic regional planning processes/spatial collaboration, and cohesion activities. This perspective arises from AEBR's extensive experience as an NGO with special consultative status with key Directorates within the European Commission, arising from AEBR's core policy and advocacy role relating to cross-border cooperation and the specific needs of cross-border regions and border regions as expressed among our membership. AEBR's membership consists of civic regional authorities and cross-border cooperation platforms drawn from every internal and external border region of the EU and beyond.

In addition, AEBR notes that our project commissioned by DG REGIO, *b-solutions*, was referenced by DG SANTE as having contributed to an awareness of the issues which have informed the specification for this study of patient mobility. Our work in this study was led and coordinated by the same personnel (Martin Guillermo and Caitriona Mullan) who respectively lead the B Solutions Project (Martin Guillermo with Cinzia Dellagiacoma/Giulia Brustia at AEBR) and quality-assured the project compendium of the first phase of B Solutions in 2020 (Caitriona Mullan).

[6] EPECS (*European Patients Empowerment for Customised Solutions*) is a network of regional patient organisations and persons interested in cross-border European healthcare. EPECS's primary objective is to safeguard the central role of citizens and patients in a rapidly developing Europe. One of EPECS's founders is Huis voor de Zorg, an independent organisation that advocates for patients in the Dutch province of Limburg. Patient mobility is in full swing in Limburg. For further information visit: https://www.epecs.eu/cross-border-healthcare/ (last retrieved on 17 July 2021)

2.0 Overall Context and Assumptions for the Study

2.1 EU Level Data on Patient Mobility

In considering the specific Member States pertaining to the case studies on selected regions which have been carried out through this research project, a snapshot of available data on cross-border patient mobility provides some baseline information.

During the project inception phase, meetings were held with each of the relevant National Contact Points who have responsibility for reporting on cross-border patient mobility under the Directive. Observations arising from these discussions are included in the case study sections of this report in Chapter 3.

Meetings with National Contact Point personnel for Member States (NCPs) relevant to the case study areas took place during the inception phase of the project in order to inform NCPs and to outline how NCPs could participate further in the study as appropriate. These meetings included an overview of the project, its focus and scope, timescales, and details on inclusion of NCPs in key elements of the process including peer review. All NCPs were invited to complete a questionnaire and were also offered an individual interview as part of the research methodology. NCPs were invited to participate in stakeholder focus groups and in the Webinar in which results and recommendations arising from the research were discussed prior to preparation of the last version of this final report.

In all NCP discussions, it was acknowledged that the fact that the reimbursement arrangements for care accessed under the Directive are complex. While the Directive provides for a prior authorisation system, most of the care under the Directive is reimbursed after care has been provided, with no prior authorisation or prior notification having been provided. Under the Regulations, where the S2 Form giving prior authorisation is required, this is not the case. The NCPs all noted that the possibility of retrospective claims under the Directive means less control and influence over the quality of data than in cases where the Social Security Regulation (S2) is used.

Patient mobility in the case study countries under the Directive and Regulations

In the present study, we sought to identify previously unreported cases of patient mobility in the border regions of four country groups. This is because anecdotal evidence, as well as reports made in the context of certain cross-border projects, indicate that some border regions have a much higher level of patient mobility than that which is reported by the NCPs. It is useful therefore to highlight the data that have been collected to date in the context of the annual data collection on the use of the Directive and the Regulation to gain a general picture of what is already known.

In considering the specific Member States relevant to the case studies on selected regions under focus in this research project, the AEBR team conducted a snapshot of available data on cross-border patient mobility as a baseline for further research. During the project inception phase, meetings were held with each of the relevant National Contact Points who have responsibility for reporting on cross-border patient mobility under the Directive.

In some cases, Member States or their agents collect a significant amount of additional data on patient demographics for cross-border patient mobility. Overall, the study team has found that accessing data relating to cross-border patient mobility is influenced by a number of factors which include the following:

- while there is a national legal requirement to report on the Directive and Regulations, the national context for the collection and sharing of patient reimbursement data and patient mobility data can vary – especially in Member States where health insurers are not national insurers; GDPR constraints on sharing are a factor in this context;
- better data collection happens where there is institutional commitment and culture that promotes data-driven processes of decision making, service planning, and performance analysis;
- social and cultural capital for cross-border healthcare collaboration in the case study regions- i.e., the degree of capacity which exists at the level of border regions and cross-border functional areas, for healthcare-related cross-border collaboration. Civil society organisations, municipalities, and Euroregion structures engaged in supporting healthcare cooperation or advocating on healthcare access issues, and health insurers engaged with regional actors and through regional operations all form part of a region's capacity in this context;
- relationships between healthcare insurers and Member State health ministries;
- relationships between healthcare insurers and regional actors;
- relationships between Member State health ministries and regional actors.

Where good quality data exists, the research focused on how this might be enhanced or complemented through cooperative approaches to using the data for statistical purposes and to ensure evidence-informed approaches to cross-border patient mobility. Where there are data gaps we examined, where possible, the reasons for these gaps and will consider recommendations to address these where feasible.

Impact of COVID-19 on patient mobility

The research, while not specifically aimed at examining the impact of the COVID-19 Pandemic on the Directive and Regulations overall, also considered the impact which the COVID-19 pandemic and responses to it may have - or may be perceived as having - on cross-border patient mobility, and whether available data shows any indications of changes in patterns e.g. in relation to reimbursement under the Directive for the cost of COVID-19 testing (as has been the case for French citizens accessing COVID-19 testing in other Member States). Our analysis also considers whether it is worthwhile for specific focuses on data in border regions for the purpose of determining how health systems may recover from the impact of COVID-19 - for example in considering the impact of the Pandemic on elective care waiting lists, and how data-informed approaches to this- based on potentially improved approaches to data collection might be part of future mobility patterns and contribute to population health outcomes in the case study regions.

Existing EU-wide data on patient mobility under the Directive (see also tables 1 & 2 on page 27/8)

In order to set the baseline for the present study, the known and validated data on patient mobility funded under the Directive in 2019 as presented in the reports published by the Commission in 2020, are set out below. While we highlight only the data for 2019 reimbursements, the data as reported for that year are not significantly different to those reported for four previous years. With respect to the Directive, the tables below show the data on claims for reimbursement when no prior authorisation is needed **(Table 1-overleaf)** and on reimbursement after prior authorisation has been provided **(Table 2-overleaf).** In each table, the numbers for the country with border regions Meuse-Rhine, Grand Est, and Lower Austria are highlighted. In each case the highlighted number indicates the reported number of claims received in the competent Member State – that is the patient's country of normal residence where statutory health insurance contributions are made. It should be noted here that the number of claims reflect episodes of care and may not necessarily reflect patient numbers as in some cases a patient will have made more than one claim.

The reported data for patient mobility under the Directive shown in Tables 1 and 2 show two significant points: first, the overall numbers are not very high, although some exceptions exist; and second, some very significant gaps exist in the data.

Table 1 shows the full EU data set on reimbursed care following the prior authorization scheme that some countries have chosen to adopt. The first remarkable issue in this table is that the numbers are much smaller than table 2, showing reimbursement for care non-requiring prior authorisation. On an aggregate basis across the EU this is because nine countries have not implemented a system of prior authorization, accordingly, table 1 shows ''not applicable" (n/a) for Cyprus, Czechia, Estonia, Finland, Latvia, Lithuania, Netherlands, Sweden, and Norway. For the countries that have implemented the system, generally, the uptake remains low. One reason for this is that in many cases the Regulations may provide a better level of funding for a patient, given then under the Regulations, the reimbursement is at the cost of the care in the Member State of treatment, while under the Directive it is at the rate that would have been reimbursed had the treatment been provided in the home country, furthermore, under the Directive, it is a reimbursement to the patient who has paid upfront, while under the Regulations the transfer of funds is between health insurers and the patient has no out-of-pocket expenses, other than transport or other costs that are not reimbursable in the home country.

In Table 2, which shows data on reimbursement for care not requiring prior authorisation, of particular note is the patient mobility reported for France. At 148,263 this accounts for just over 60% of all patient mobility with prior authorisation under the Directive. This number must, however, be treated with caution, as it reflects a particular problem France has acknowledged in reporting data on patient mobility, namely that France cannot distinguish between reimbursements for cross-border care made under the Directive regime and under the Regulations regime, being able to identify only certain types of care, such as care for fertility treatment, as having been reimbursed under the Regulations. As a result, all cases that did not fall into a small group of classes of care were included as care reimbursed under the Directive. France has noted that while it can for certain types of care identify if the Directive or Regulation governed the reimbursement made, in the majority of cases this is not possible.

In addition to the problem noted in France's data reporting, it must be noted that Table 2 does not include data from Belgium, Germany, Hungary, Luxemburg, and the Netherlands. Belgium noted that this arose because not all health insurance funds were able to report, and they preferred not to provide partially complete data. The Netherlands reported that the Dutch healthcare system is implemented by private health insurers, with a range of data recording systems varying widely, making it very difficult to aggregate data at a national level. This is very similar to the reason set out by Germany, who also cited the high number of health insurers who each handle patient claims independently and do not report their data at national level. Hungary and Luxemburg did not provide any data on mobility not requiring prior authorization but did not provide any reason as to why the data were missing. The impact of these data gaps is that information on patient mobility is missing for roughly 23 % of the potential population that could avail of the right to receive healthcare in another country under the rules of the Directive.

Table 1: Existing EU-Wide Data on Patient Mobility: Reimbursement of Cross-border Care under Directive- 2019- With Prior Authorisation

	AT	BE	BG	HR	CY	CZ	DK	EE	FI	FR	DE	EL	HU	IE	IT	LV	LI	LT	LU	MT	NL	PL	PT	RO	SK	SL	ES	SE	UK	NO	IC	SENT
Austria	0	0	0	0	0	0	0	0	0	0	4	0	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	**6**
Belgium	0	0	0	0	0	0	0	0	0	8	0	0	0	0	1	0	0	0	0	0	6	0	0	0	0	0	0	0	1	0	0	**16**
Bulgaria	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	**2**
Croatia	0	0	0	0	0	0	0	0	0	0	0	0	0		0	0	0	0		0	0	0	0	0	0	0	0	0	0		0	**0**
Cyprus	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	
Czech repub	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	
Denmark	2	1	0	0	0	0	0	0	0	0	7	0	0	0	0	0	0	0	0	0	1	3	0	0	0	0	2	2	1	0	0	**19**
Estonia	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	
Finland	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	
France	6	130	2	1	0	0	0	0	1	0	442	0	2	0	20	0	0	0	138	1	3	4	0	1	0	0	0	1	8	0	0	**760**
Germany	Not Available																															
Greece	0	1	0	0	0	0	0	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	**5**
Hungary	100	3	0	0	0	0	0	0	0	3	64	0	0	0	4	0	0	0	0	0	0	1	0	0	0	0	5	0	4	0	0	**184**
Ireland	0	4	0	1	0	1	0	0	1	1	6	0	2	0	3	1	0	5	0	0	0	26	1	1	0	0	3	0	1330	0	0	**1386**
Italy	31	1	0	0	0	2	0	0	0	3	16	1	0	0	0	0	0	0	1	0	0	0	0	0	0	0	3	1	1	0	0	**60**
Latvia	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	
Lithuania	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	
Luxembourg	9	53	3	0	1	4	1	0	0	14	490	2	2	0	6	0	0	1	0	0	1	5	82	0	0	0	26	0	3	0	0	**703**
Malta	0	0	0	0	0	0	0	0	0	0	3	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	2	0	2	0	0	**8**
Netherlands	not available																															
Poland	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	**0**
Portugal	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	**0**
Romania	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	**2**
Slovakia	4	0	0	0	0	305	0	0	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	**311**
Slovenia	1	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	**3**
Spain	0	1	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	**2**
Sweden	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	
UK	0	1	1	0	9	2	0	1	0	16	4	2	2	1024	7	5	0	301	0	0	2	20	0	2	1	0	26	1	0	0	0	**1427**
Norway	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	**0**
Iceland	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	5	0	0	0	0	0	0	1	0	0	**8**
TOTALS RECEIVED	**153**	**196**	**6**	**4**	**10**	**314**	**1**	**1**	**2**	**49**	**1041**	**5**	**8**	**1024**	**44**	**7**	**0**	**307**	**139**	**1**	**13**	**64**	**83**	**4**	**1**	**0**	**67**	**5**	**1353**	**0**	**0**	**4902**

n/a - countries not applying a system of Prior Authorisation; not available - cases may exist, but data were not reports; 0 no reimbursements made, note that in most cases applications were made but were not successful

Table 2: Existing EU-Wide Data on Patient Mobility: Reimbursement of Cross-border Care under Directive- 2019- where Prior Authorisation is not applicable

	AT	BE	BG	HR	CY	CZ	DK	EE	FI	FR	DE	EL	HU	IE	IT	LV	LI	LT	LU	MT	NL	PL	PT	RO	SK	SL	ES	SE	UK	NO	IC	SENT
Austria	0	0	0	0	0	0	0	0	0	0	0	3	0	0	0	0	0	0	0	0	0	0	0	0	0	0	4	0	0	0	0	**7**
Belgium	not available																															
Bulgaria	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	**0**
Croatia	22	11	0	0	1	6	0	0	4	7	123	1	3	1	5	0	0	0	1	0	6	0	2	0	1	20	3	2	1	1	0	**221**
Cyprus	0	0	0	0	0	0	0	0	0	0	2	6	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	5	0	0	**13**
Czech Rep	197	1	2	0	0	0	0	0	0	4	539	3	0	0	6	0	0	0	1	0	3	17	1	0	130	1	7	0	4	0	0	**916**
Denmark	311	18	32	57	32	25	0	1	13	288	17352	119	528	7	182	18	0	52	2	35	103	1007	74	26	10	1	1813	3298	35	40	3	**25,482**
Estonia	0	1	6	0	2	2	1	0	21	2	16	4	0	0	1	26	0	3	0	1	5	2	0	0	0	0	17	3	0	3	0	**116**
Findland	7	23	10	6	1	11	4	5301	0	35	65	17	57	2	16	38	0	12	0	0	9	90	16	9	13	3	489	53	6	2	0	**6,295**
France	1295	30881	1058	784	211	479	60	46	284	0	8661	5240	3794	549	8006	108	8	111	13235	405	1575	2584	32766	1146	128	132	33427	179	900	116	95	**148,263**
Germany	not available																															
Greece	1	13	0	0	7	1	0	0	0	10	10	0	0	0	10	0	0	0	2	0	0	0	0	0	0	0	1	0	8	1	0	**64**
Hungary	not available																															
Ireland	0	3	1	1	0	3	0	1	0	3	21	0	2	0	3	4	0	19	0	0	3	122	0	1	1	0	7	0	3943	0	0	**4,138**
Italy	112	3	0	13	0	1	0	0	0	7	20	2	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	**159**
Latvia	0	0	0	2	0	0	0	2	0	0	6	0	0	0	0	0	3	0	0	0	0	1	0	0	0	0	1	0	0	0	0	**15**
Lithuania	1	1	0	0	0	1	0	7	0	2	22	0	0	0	0	64	0	0	1	0	0	25	0	0	11	0	2	4	2	0	0	**143**
Luxembourg	not available																															
Malta	0	1	0	0	0	0	0	0	0	2	0	0	0	0	1	0	0	0	0	0	1	0	0	0	0	0	0	0	9	0	0	**14**
Netherlands	not available																															
Poland	13	1	0	3	0	14171	0	0	0	6	453	0	0	3	22	0	0	783	0	0	1	0	0	0	53	0	63	0	2	0	0	**15,574**
Portugal	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Romania	53	3	0	0	0	0	0	0	0	13	60	2	729	0	28	0	0	0	0	0	2	0	3	0	0	0	5	0	3	0	0	**901**
Slovakia	361	7	6	11	2	5109	0	0	0	11	88	4	529	0	11	1	0	2	4	0	11	4121	2	5	0	1	7	1	8	0	0	**10,302**
Slovenia	179	0	0	890	0	5	0	0	0	0	28	0	19	0	442	0	0	0	0	0	2	0	0	1	0	0	3	0	6	0	0	**1,575**
Spain	1	0	0	0	0	0	0	0	0	1	1	0	0	0	1	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	**5**
Sweden	529	79	83	282	209	50	3040	37	1082	802	784	1084	53	12	319	25	0	42	12	34	107	240	192	47	9	14	7926	0	117	86	19	**17,315**
UK	19	12	56	6	17	44	0	6	0	136	107	24	45	70	33	83	0	318	0	0	19	850	8	44	49	4	94	0	0	1	1	**2,046**
Norway	43	24	36	51	123	18	124	8	19	88	270	212	429	7	34	27	1	84	2	0	121	577	35	13	18	6	8148	103	32	0	20	**10,673**
Iceland	1	1	0	0	0	5	3	2	1	5	5	3	413	3	3	3	0	6	0	0	3	181	1	3	0	2	326	6	16	2	0	**994**
TOTALS RECEIVED	**3,145**	**31,083**	**1,290**	**2,106**	**605**	**19,931**	**3,232**	**5,411**	**1,424**	**1,422**	**28,633**	**6,724**	**6,601**	**654**	**9,123**	**397**	**12**	**1,432**	**13,260**	**475**	**1,972**	**9,817**	**33,100**	**1,295**	**424**	**184**	**52,343**	**3,649**	**5,097**	**252**	**138**	**245,231**

n/a - countries not applying a system of Prior Authorisation

not available - cases may exist, but data were not reports

0 no reimbursements made, note that in most cases applications were made but were not successful

2.2 Literature Review

There are three contexts in which literature reviewed in this study is referenced and presented:

- Literature which contextualises the overall project and the reasons for its focus;
- Literature reviewed which has relevance for case studies- this is referenced directly within the case studies; (a recent example of this is the recently published Maastricht University ex-ante report on the role of the Directive in cross-border regions)[7];
- Literature reviewed which has relevance for themes emerging from the case studies, recommendations (specific and general)- this is referenced where relevant in findings, conclusions, and recommendations.

Literature setting the Context for the Study:

An initial literature review of official documentation and publications of the European Commission relating to the Directive[8]- including a review of the text of the Directorate itself- provides some basic assumptions which can be usefully highlighted in further illustrating the context for this research project.

The preamble to the Directive itself outlines the key principles relating to the implementation of the Directive in detail- these include that sufficient information should be available for citizens in order to facilitate informed decisions about seeking healthcare in another Member State and that Member States themselves have discretion to decide whether prior authorisation of the care sought in another Member State is necessary. The key role of National Contact Points is a legal requirement under Article 6 of the Directive. In this study, we have focused on case study regions where sub-national and cross-border regional partnerships may be shown to have a key perspective or role in fulfilling the objective of the Directive as it applies to cross-border regions. Border regions are specifically referenced in the Directive as potentially benefitting from additional cooperation between stakeholders given the particular conditions in border areas created by the interface and interaction between respective national Member State systems.

On data, and in particular the issue of cooperation on data within Member States' own national healthcare systems, paragraph 49 of the preamble of the Directive also states that 'the existence of National Contact Points should not preclude Member States from establishing other linked contact points at regional or local level, reflecting the specific organisation of their healthcare system.'

Paragraph 50 of the Preamble states that: 'Member States should facilitate cooperation between healthcare providers, purchasers and regulators of different Member States at national, regional or local level in order to ensure safe, high-quality and efficient cross-border healthcare. This could be of particular importance in border

[7] Maastricht University Institute for Transnational and Euregional cross-border cooperation and mobility (ITEM): *Cross-Border Impact Assessment 2021 Dossier 4: Is the EU Patient's Rights Directive fit for providing well-functioning healthcare in cross-border regions? An ex-post assessment* (2021)

[8] DIRECTIVE 2011/24/EU OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 9 March 2011 on the application of patients' rights in cross-border healthcare

regions, where cross-border provision of services may be the most efficient way of organising health services for the local population, but where achieving such cross-border provision on a sustained basis requires cooperation between the health systems of different Member States. Such cooperation may concern joint planning, mutual recognition, or adaptation of procedures
or standards, interoperability of respective national information and communication technology (hereinafter 'ICT') systems, practical mechanisms to ensure continuity of care or practical facilitating of cross-border provision of healthcare by health professionals on a temporary or occasional basis.'

The focus of this study is to complement the information collected under Article 20 of the Directive and to identify recommendations for future approaches to data collection:

'Article 20 Reports 1. The Commission shall by 25 October 2015 and subsequently every 3 years thereafter, draw up a report on the operation of this Directive and submit it to the European Parliament and to the Council. 2. The report shall in particular include information on patient flows, financial dimensions of patient mobility, the implementation of Article 7(9) and Article 8, and on the functioning of the European Reference Networks and National Contact Points. To this end, the Commission shall conduct an assessment of the systems and practices put in place in the Member States, in the light of the requirements of this Directive and the other Union legislation relating to patient mobility. L 88/64 Official Journal of the European Union 4.4.2011 EN The Member States shall provide the Commission with assistance and all available information for carrying out the assessment and preparing the reports.'

The Commission's 2018 report to Parliament and Council further states that: 'it may be estimated that cross-border with PA under the Directive amounts to approximately 6% of the authorised treatments in another Member State. However, this estimate should be interpreted with some caution because, as noted above, not all Member States are able to fully separate those claims made under the Directive and those made under the Regulations'[9].

The value of conducting case studies on patient mobility in border regions builds on a key factor which is a driver for cross-border patient flow and doubly so in border regions where the nearest point of relevant care may be in a neighbouring Member State. The Commission's 2018 Cross-border Care report stated[10] that 'in line with a pool of previous studies, our findings point to the importance of geographical and cultural factors in driving cross-border healthcare collaboration'.

In this sense, in border regions where the closest point of relevant care for a patient may be in a neighbouring Member State, a study of patient mobility in selected cross-border regions, also serves to illustrate possible added value pathways and identify considerations that may be useful in the context of future implementation of the Directive to the increased benefit of EU citizens.

[9] Ibid; p8.

[10] European Commission (2018) *Study on Cross-Border Cooperation Capitalising on existing initiatives for cooperation in cross-border regions Cross-border Care Final report; p22.*

Drawing on this conclusion, the Commission's 2018 Report to the European Parliament and the Council refers to the specific opportunities which exist for economies of scale in border regions which can be achieved through collaboration and innovation, without significant disruption to normal business for Member States' operation or financing of healthcare; the Commission's report concludes:; 'Now, after five years of the operation of the Directive, it can be concluded that cross-border patient flows are showing a stable pattern, mostly driven by geographical or cultural proximity. Overall, patient mobility and its financial dimension within the EU remain relatively low and the Cross-border Healthcare Directive has not resulted in a major budgetary impact on the sustainability of health systems' (p17)[11].

A detailed report by the European Court of Auditors in 2019[12] concluded that the European Commission had worked well to support Member States and in supporting the implementation of measures to support cross-border healthcare. It also stated that 'while EU actions in cross-border healthcare were ambitious and enhanced Member States collaboration, they require better management. The impact on patients was limited at the time of our audit'.

While this study is concerned primarily with a focus on data collection patterns for cross-border patient mobility, identifying the reasons why there may be gaps in data, and recommending potential approaches to improving data collection in the future, it is difficult to consider the issue of data in isolation from the matter of what lies behind quantitative figures and what may ultimately explain figures in a way which can inform action, improvement or a fuller understanding of cross - border patient mobility.

The issue of data gaps on the implementation of the Directive, and data on cross-border mobility in general, needs to be understood in a wider context of the point at which the EU is moving towards a more comprehensively data-driven model of integration and cohesion. Data gaps also provide an indicator of the extent of outstanding opportunities which exist for the EU big data agenda to facilitate and assist with health sectoral objectives. Writing in an independent academic article in 2015 on the challenges and opportunities of big health data in Europe, Salas Vega et al[13]. recommended that 'sitting within Europe's political and legislative hub, EU policymakers should give greater clarity to big data governance in health care, particularly as it applies to cross-border data use.' They further stated that 'the statistical service of the EU, Eurostat (EC), has already created a Big Data Task Force to refine use of big data for European official statistics. This task force, however, does not focus on data use in health but rather on its application to all EU statistics. Given the unique challenges associated with health data, 174 EU policymakers should consider 'creating expert teams to oversee EU health data quality initiatives. The article goes on to note that at the point of publication, the work on health-specific big data was in its infancy.

[11] Ibid; p17.

[12] European Court of Auditors (2019) *Special Report EU actions for cross-border healthcare: significant ambitions but improved management required (pursuant to Article 287(4), second subparagraph, TFEU);* paragraph 67.

[13] Sebastian Salas-Vega, Adria Haimann & Elias Mossialos (2015) *Big Data and Health Care: Challenges and Opportunities for Coordinated Policy Development in the EU, Health Systems & Reform,* 1:4, 285-300, DOI: 10.1080/23288604.2015.1091538; last accessed on 22.09.2021

Consequently, and with reference to the ongoing work now much advanced in the European Health Data Space, in this study we explore recommendations on data collection within the context of regional collaboratives involving subnational, regional, and national actors (NCPs). These suggested solutions may provide the essential operational/territorial link components for the translation of the EU big data agenda into implementational contexts which can contribute to better data on patient mobility- and which are also located within spatial development models on borders which can enable a cross-border data-driven approach both health sector and wider population objectives.

Despite documented challenges, the Directive remains a highly relevant legal framework for the delivery of patient rights across Europe. EUREGHA, a network and advocacy platform of local and regional health authorities across Europe[14], in its 2018 position paper on the Future of Health in Europe[15], notes that there is a significant role for the EU in adding value for European Citizens in the area of health:

'A clear example of the EU added value is the Directive 2011/24/EU on patients' rights in cross-border healthcare. Adopted in 2011, it was an important step forward for European health policies, responding to the needs of EU citizens.'[16]

The EUREGHA 2018 paper also notes that the degree to which the directive is implemented to its full potential 'varies between Member States and regions and more needs to be done to overcome some of the challenges, for example, related to documentation, translation and equal access' but concludes that the Directive implemented to its full potential still 'guarantees patients' rights to access safe and high-quality healthcare across national borders in the EU and their right to be reimbursed for such healthcare'.

Illustration of these issues is found also and specifically in respect of people with disabilities accessing cross-border healthcare in the joint report by the International Federation for Spina Bifida and Hydrocephalus (IF), the European Disability Forum (EDF), and the European Patients' Forum (EPF) on the Impact of Cross-border Healthcare on Persons with Disabilities and Chronic Conditions[17]. This report highlights that a survey conducted by these three organisations revealed that 86% of respondents were unaware of the NCP information point and that disability and patient advocacy organisations can play a role in working with NCPs to improve accessibility of information to persons with disabilities and chronic conditions. The authors of the report highlight the difficulties with obtaining quantitative data on patient mobility of people with disabilities and chronic conditions and point to gaps in qualitative data from respondents arising from a lack of experience of using cross-

[14] About us | EUREGHA
[15] EUREGHA (2018): *Health in All Regions: EUREGHA's Position on the Future of Health in Europe beyond 2020*
[16] EUREGHA (2018): *Health in All Regions: EUREGHA's Position on the Future of Health in Europe beyond 2020; p2.*
[17] IF/EDF/EPF (2016): *Impact of cross-bord**er** healthcare on persons with disabilities and chronic conditions.*

border mobility mechanisms. A key finding of the report[18] highlights issues around reimbursement of full costs of accessing care (such as travel costs for personal assistants to people with disabilities) and the impact that discretionary decisions by the insurer can have on the patients' ability to access their right to cross-border care without prohibitive factors such as un-reimbursed costs. These issues were also borne out by examples given by stakeholders during our research. The report emphasises the benefits and crucial role of the NCPs in actively engaging in relation to the provision of information for persons with disabilities and chronic conditions. It also recommends that 'Member States' use of their discretion to reimburse the additional costs incurred during cross-border healthcare must be in line with the UN CRPD in order to avoid discrimination of persons with disabilities and patients with chronic conditions, who are most likely to have additional costs[19].'

With better patient mobility data, it is clear from literature reviewed that NCPs and Member States would be enabled to measure their impact on more vulnerable citizen groups, adopt best practice, and also allow evidence-informed planning of services to take place both at home and on a cross-border basis. The usefulness of better data relating to the use of patient mobility mechanisms by people with disabilities, chronic conditions, and rare diseases is referenced in the findings analysis and the conclusions of this study.

Importantly, the EUREGHA paper reference above also emphasises the relevance and importance of creating new strategic relationships with local and regional authorities for health, and of the development of multi-stakeholder working relationships which involve- crucially- the competent authorities and partners (including the healthcare sector, civil society organisations, and the third level academic sector) in order to achieve progress[20]. These partnerships are necessary to support the necessary networking, exchange of perspectives, and understanding required to tackle health inequalities through a shift to a value-based approach to delivery that delivers both efficiency and optimal outcomes which are meaningful to the individual patient. The issue of multi-stakeholder collaborative working to develop pathways to better cross-border patient mobility data, and which sets this in a wider context of shared purpose is a theme to which we will return in our final chapter of the report.

EUREGHA and *Healthacross*- the latter being a direct respondent stakeholder in our case study of Lower Austria/Bohemia/Slovakia, also published a paper in 2019 on healthcare in cross-border regions which calls for a range of policy actions including innovative action in relation to financing and reimbursement of care across borders. In addition to calling for mapping and understanding of payment and reimbursement arrangements and practice in border regions (which is a focus in our case studies), the position paper calls for innovative solutions in the area of financing (particularly relevant in relation to the Directive's current requirement for patients to pay the cost of their care upfront and prior to reimbursement) and also calls for collaborative

[18] IF/EDF/EPF (2016): *Impact of cross-bord**er** healthcare on persons with disabilities and chronic conditions; p2.*

[19] IF/EDF/EPF (2016): *Impact of cross-bord**er** healthcare on persons with disabilities and chronic conditions; p9.*

[20] EUREGHA (2018): *Health in All Regions: EUREGHA's Position on the Future of Health in Europe beyond 2020; p4.*

working and networking between insurers.[21] This paper also reinforces the relevance of bottom-up, regionally-anchored approaches in cross-border areas for addressing the specific difficulties which arise in border regions from the complexities of the 'different structures and principles' of the two main EU legal mechanisms governing the cost reimbursement of cross-border patient care- namely the Social Security Regulations and the Directive. Our case studies draw out the relevance of capacity at cross-border regional level which represents this necessary bottom-up approach required to give meaning to these legislative macro-frameworks in an applied territorial context.

Gabriela Bergki's 2015 thesis on cross-border patient mobility and the legal framework of obtaining healthcare abroad within the European Union[22] focuses on the unreleased potential of the Directive- at the time of publication- to deliver on the rights of patients. She states that it is essential to provide 'European patients with a coherent, clear and logical legal framework, which enables them to claim their right to cross-border patient mobility when in need, is of high importance'[23]. The thesis examines the particular obstacles to this arising from some of the conditions of implementation of the Directive as well as how conditions for implementation of both the Directive and the Social Security Regulations create complexities through which it can be difficult and at times prohibitive for the individual citizen to navigate. Bergki's recommendations include the establishment of a financial innovation in a European Healthcare Fund, and the importance of interoperable ICT-based solutions to give full expression to patient mobility rights across borders.

On the matter of good quality cross-border patient mobility data, she quotes a body of cross-border healthcare expert research carried out by various individuals (including some who have contributed directly to the AEBR study)[24] pointing out that cross-

[21] EUHPP Thematic Network on Healthcare in Cross-border Regions (EUREGHA & Healthacross) (2019): *Joint Statement- Recommendations for Policy Actions;* p8.

[22] Gabriela Bergki (2015): *CROSS-BORDER PATIENT MOBILITY: THE LEGAL FRAMEWORK OF OBTAINING HEALTHCARE ABROAD WITHIN THE EUROPEAN UNION – A PATIENT'S PERSPECTIVE; University of Ghent.*

[23] Gabriela Bergki (2015): *CROSS-BORDER PATIENT MOBILITY: THE LEGAL FRAMEWORK OF OBTAINING HEALTHCARE ABROAD WITHIN THE EUROPEAN UNION – A PATIENT'S PERSPECTIVE; University of Ghent; p3.*

[24] Bergki (2015) quoting references: Willy PALM, Jason NICKLESS, Henri LEWALLE and Alain COHEUR (2000): Implications of recent jurisprudence on the co-ordination of health care protection systems. Association Internationale de la Mutualite, http://www.ose.be/health/files/KDsyntEN.PDF (7 November 2012), p. 7; Irene A. GLINOS and Rita BAETEN (2006): A Literature Review of Cross-Border Patient Mobility in the European Union. Brussels: European Observatory on Health Systems and Policies, Europe for Patients Project, http://www.ose.be/files/publication/health/WP12_lit_review_final.pdf (15 October 2012), p. 6; Irene A. GLINOS, Rita BAETEN, Matthias HELBLE and Hans MAARSE (2010): A typology of cross-border patient mobility. Health and Place, Vol 16 Issue 6, p. 1147; Helena LEGIDO-QUIGLEY, Irene A. GLINOS, Rita BAETEN, Martin MCKEE, Reinhard BUSSE (2012): Analysing arrangements for cross-border mobility of patients in the European Union: A proposal for a framework. Health Policy, Vol 108 Issue 1, p. 27. See also COM (2008) 415, p. 8 and Recital 39 of the Preamble of Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients‟ rights in cross-border healthcare. OJ L 88 of 4 April 2011. 4 George FRANCE (1997): Cross-border flows of Italian patients within the European Union - An international trade approach. European Journal of Public Health, Vol 7 Suppl 3, p. 18. See also PALM et al. (2000: 7.).

border patient movements are considered '"non-marginal for certain pathologies and/or geographical areas in particular countries." They are highly significant especially (1) in border regions, (2) for smaller Member States, (3) for rare diseases, (4) in areas that attract a large number of tourists.'

In our research conclusions and recommendations, we further explore the idea that, in the context of European Integration (and tackling problems such as gaps in data on patient mobility, there are necessary territorially focused practices that are required to underpin a transformation of border regions from being areas where National systems stop with the risk of anomalous outcomes for citizens, to being areas where National systems act in confluence. Understanding border regions as an essential component of integration across the entire EU and on its external borders, enables the conceptual reframing of border regions in European terms as central rather than peripheral to the EU integration agenda and as zones of Member State territories where Member States can develop solutions which can benefit the wider national community. In this light, of note is a recent report by the European Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, published in July 2021, also highlights border regions as 'living labs' for the applied practices which underpin European integration.

This report highlights the role of border regions- often peripheral in a domestic Member State context- as central to the process of European Integration. In respect of healthcare, it highlights that financing and reimbursement issues remain a major complexity in the development of cross-border healthcare solutions and cites the Healthacross example of delivery as a model of good practice.[25] It also refers to the learning from the European Commission's *b-solutions project*- delivered and managed by AEBR- as highlighting where a European Cross-border Mechanism (ECBM) could potentially be used as a legal mechanism for certain competencies to be exercised by local and regional cross-border authorities/collaboratives, and points to the fact that resolution of prevailing obstacles to cross-border cooperation and integration often requires careful legislative facilitation. Our final recommendations of this study relate to both what is possible within the current legal framework and point also to where additional legislative action at a European level- such as that in the Health Data Space, will further enable integration processes at borders in relation to cross-border healthcare and population health, underpinned by good data on patient mobility as an indicator of facilitative conditions at grassroots/local level on borders. We also expand upon the issue of the relevance of solutions in border regions for other regions.

This study and report have aimed to identify pathways to improved data collection on cross-border patient mobility including that collected for the purposes of reporting on future implementation of the Directive. In doing so we have drawn a number of policy action strands together which demonstrate the multi-level, evidence-based approaches which will be necessary for sustainable change and progress towards better data collection, and which locate this issue in an implementational context of border regions, which have the potential to contribute solutions for more general application across the EU. A review of an article on European Groupings for Territorial

[25] EUROPEAN COMMISSION Brussels, 14.7.2021 COM(2021); *393 final REPORT FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT, THE COUNCIL, THE EUROPEAN ECONOMIC AND SOCIAL COMMITTEE AND THE COMMITTEE OF THE REGIONS EU Border Regions: Living labs of European integration; p5.*

Cooperation by Mission MOT Director Jean Peyrony[26] in a publication edited by Gyula Ocskay, Secretary-General of CESCI, provides some useful theoretical context for the recommendations of this study.

Peyrony explores the issue of functional territories and the consideration of multi-level governance required for the effective functioning of border regions. Much of what he writes about functional regions can be usefully considered as it relates to the domain of cross-border health and patient mobility, such as the identification of cross-border patient populations/catchments and the conditions required to underpin a territorial synthesis for the rights of patients as derived both from the Member State and as EU citizens by virtue of their Member State's endorsement of EU mechanisms and legislation. In this sense, the exploration of cross-border access and planning of healthcare, using the legal mechanisms available under EU law such as the Directive and the Regulation, can be as much about providing templates and frameworks for the full expression of citizens' rights through the lens of healthcare, access to healthcare, and addressing health inequalities.

The paradigm of citizen rights in border regions and where across the border is 'home' or 'local' is a more helpful one which can inform innovation in collaborative, inter-institutional approaches to creating access to healthcare across borders for the populations of border regions- and one which enhances the competitiveness of both the care and the health insurance products offered to citizens. A recent report by Maastricht University's ITEM[27] -(Maastricht University is also a key institution within the Meuse-Rhein case study in Chapter 3A of this report)- also notes that 'border regions may lack adequate healthcare services due to their peripheral location and unique demographics, necessitating the availability of these services across the border.' The Maastricht University report highlights a further important observation in people in border regions who access care across the border perceive that access. 'Border region inhabitants as healthcare users also distinguish themselves from domestic users, 'medical tourists' or even frontier workers, in that they may have a structural need for healthcare services across the border. Thus, cross-border healthcare provision may foster economic, social, territorial cohesion and Sustainable Development in border regions'[28]. In our conclusions and recommendations, we also explore the connections between better data on patient mobility, spatial planning, smart regions, and the overall impact that a connected, multistakeholder approach can have on cohesion and integration in border regions.

Both of these theoretical concepts are relevant for the future implementation of the

[26] Jean Peyrony*: Should EGTCs have competences, and not only tasks? Underlying visions of cross-border integration* in Ocskay, Gy (ed) (2020) 15 years of the EGTCs. Lessons learnt and future perspectives. Central European Service for Cross-border Initiatives (CESCI), Budapest, pp. 219-244. / ISBN 978-615-81265-1-9

[27] Maastricht University Institute for Transnational and Euregional cross-border cooperation and mobility (ITEM): *Cross-Border Impact Assessment 2021 Dossier 4: Is the EU Patient's Rights Directive fit for providing well-functioning healthcare in cross-border regions? An ex-post assessment* (2021); p26.

[28] Maastricht University Institute for Transnational and Euregional cross-border cooperation and mobility (ITEM): *Cross-Border Impact Assessment 2021 Dossier 4: Is the EU Patient's Rights Directive fit for providing well-functioning healthcare in cross-border regions? An ex-post assessment* (2021); p26/27.

Directive overall, and, by implication, can act as guiding concepts for the development of successful approaches to improved data collection as an indicator of the impact of the Directive with regard to its core objective of facilitating the rights of patients in cross-border healthcare. In our recommendations, we explore solutions that can demonstrate the concept of 'Active Subsidiarity'[29]- where the establishment of multi-stakeholder and multi-level relationships involving Member States and Subnational/regional actors can form a soft space governance and facilitative 'laboratory' in border regions for the development, testing and fine-tuning of solutions in the area of data collection on patient mobility.

This study makes recommendations for future data collection on cross-border patient mobility which are rooted within a wider context of governance and collaborative/interconnected ecosystems for regional cross-border cooperation in health, healthcare, and wider regional development. This is in recognition of the specific importance for border regions of well-functioning intersectionality between health governance, healthcare access, and territorial cross-border mobility. Our recommendations are based on the idea that 'law and policy from non-health sectors is as important for EU health governance as the body of law and policy that explicitly targets health'.[30]

The 2021 European Parliament Report on Cross-border Cooperation in Healthcare, requested by the REGI Committee, commissioned by DG IPOL (European Commission's Department for Structural and Cohesion Policies) and authored by the University of Louvain, puts forward a number of recommendations which also align with recommendations of this study on future data collection and the context in which that should take place, which should be characterised by 'simplified and disseminated information, a common cross-border language for healthcare operators, the collection and production of comparable data and mapping of healthcare institutions, the promotion of joint supply of healthcare, and the increased involvement of intermediaries'[31]. The recommendations of this study are, overall, located within and relevant to a wider emerging policy and practice context for cross-border patient mobility and territorial/administrative approaches to data collection in general. The study, in its overall findings, reaches the conclusion that better data on patient mobility depends on the effectiveness of complementary mechanisms below the level of the Member State; and that border regions not only have specific needs for good data on patient mobility but can also offer useful mechanisms for Member States in innovative approaches to future data collection.

2.3 Stakeholder Survey

The Stakeholder Survey was a qualitative action designed to further refine the research process with key stakeholders and does not in itself hold statistical value- as outlined in the sections in this report on project methodology, it was issued to respondents identified in the stakeholder mapping and was designed to flag potential respondents who may have access to or work with data of potential value to the study. In this

[29] Mullan, Wilson, Guillermo, AEBR (2021).

[30] Eleanor Brooks, Mary Guy: *EU health law and policy: shaping a future research agenda* in Health Economics, Policy and Law (2021), 16, 1–7 doi:10.1017/S1744133120000274; p5.

[31] Leloup, F 2021, Research for REGI Committee – Cross-border cooperation in healthcare, European Parliament, Policy Department for Structural and Cohesion Policies, Brussels

sense, the survey expanded on profiling stakeholders in terms of their roles and remits, in order to inform a customised approach to interviews and to focus groups. Data protection and privacy procedures were observed in the processing of the data arising from the survey. A copy of the full survey is contained in Appendix C- Detailed Study Methodology and Survey Questionnaire.

AEBR designed, administered, and issued a professionally translated and quality-assured multilingual online survey questionnaire to 218 respondents using the EU Survey tool. The survey and all supporting documentation were published in English, German, French, Dutch, Czech, and Slovak. The survey also included a question in which participants were invited to indicate their language preferences if invited to interview. Further language support and interpreting support including for Polish were provided during focus groups and interviews as required.

This survey was launched in early May, with invitations to complete the survey issued to 218 stakeholders. The survey received 50 responses. Stakeholders indicating in their response to the survey questionnaire that they had access to data/were willing to share data were contacted and interviewed; the research team has maintained liaison throughout with these stakeholders for checking and validation purposes.

The survey was essentially a mapping exercise to ascertain where respondents might hold or have access to important sources of data relevant to the study. As a component in a research process, the survey questionnaire's purpose was to identify potential sources of additional data for follow-up as well as provide perspectives on key questions around ease of access to information, reimbursement processes, and the perceived impact of COVID-19 on cross-border patient mobility. The questionnaire, therefore, aimed to elicit qualitative information and did not have a statistical purpose in and of itself. In this context, the research team consider that the rate of response and the quality of responses received are both positive and have contributed significantly to the overall research process. Where there were qualitative findings from the survey the substantive points have been incorporated into the case studies.

Chapter 3.0 - Case Studies

This chapter is divided into four separate sections in which we report on the four case studies. These are:

3A: Meuse Rhine
3B: Grand Est (France) - Luxembourg)
3C: Lower Austria/South Bohemia/Slovakia
3D: Poland/Czechia

3A Case Study 1: Meuse Rhine Region

3A Table of Contents - Case Study 1- Meuse Rhine Region

Meuse Rhine Limburg Province in NL, Aachen district in DE, and the German Speaking Community in BE	**Summary of Findings - Key aspects of cross-border patient mobility** **Key players**: Euregio Meuse-Rhine, EPECS, EU Prevent, AOK Rhineland Hamburg Insurance (DE), CZ Insurance (NL), VGZ Insurance (NL) **Sources of information:** Responses to questionnaire, interviews with representatives of AOK Rhineland Hamburg, representatives of CZ Verzekering, 2020 Annual Report on Directive, 2020 Annual Report on Regulations (both citing 2019 data)
***Who** are the key players?* • ***Who** uses care?* • ***Who** informs care?*	• Cross-border care is used mainly by people living in proximity of a hospital located across the border - notably Aachen University Hospital for patients on the Netherlands and Belgian side of the border. For German patients, specialist care is often more accessible in the Netherlands rather than in Germany which would require a long car journey. • Many patients living in the border region are heavily dependent on cross-border care, in particular those with chronic conditions who need frequent expert care. • Patients are informed by primary care providers (particularly in NL where a referral is needed) and by insurance information points. Insurers believe NCP website information is rarely used. EUPrevent, EPECS, and other not-for-profit organizations also play an important information provision role.
***What** cross-border care is accessed?* • ***What** types of care are accessed?* • ***What** influences patient mobility?*	• Patients using the AOK/CZ cross-border card access all types of care. Patients from Germany also access primary care in the Netherlands. • Some clinical specialisations have established routine use of cross-border care. In some cases, this has been based on high demand and waiting lists in one country driving access to care in another, these care needs may be relatively short term. • Significant academic collaborations between the major teaching hospitals in the region drive awareness of the potential of cross-border care among healthcare professionals, in particular for rare-disease patients. • Language facility for patients who wish to access care in the language of the country over the border, which may be their first language. • Ease of use of a pre-authorised card system, over administrative complexity of the Directive and Regulations, the Regulation system is seen as too complex and the Directive system too costly for patients who will not get full reimbursement.
How** is cross-care reimbursed?* • ***Regulation	• Very low numbers are reported of use of the Regulations and Directive in the Meuse Rhine region, primarily because the NCPs are not able to aggregate numbers from a large number of insurance providers. • **Regulations** - **Germany** was not able to report data on issue or receipt of PDS2 forms under the Regulation; at national level, the **Netherlands** reported issuing 3,044 PDS2 in total for care in another country but not country-level data (Insurers CZ reported an

	issue of 89 PDS2 for care in Germany), the total number of PDS2 received in NL from Germany was 2,667, and 232 from Belgium; **Belgium** reported issuing 62 PDS2s for treatment in Germany and receiving 93, and issuing 28 for treatment in the Netherlands and receiving 1,006.
• ***Directive***	• **Directive** – Germany, Netherlands, and Belgium were not able to provide data on reimbursement under the Directive for care not requiring Prior Authorisation (PA) citing lack of capacity to collect data in a uniform way from the many insurance providers in each country. Only **Belgium** was able to report in mobility based on Prior Authorisation (PA), reporting 6 cases to NL. NL does not operate a PA system. Insurer CZ separately reported having reimbursed 852 episodes of care in DE for its insured patients across NL under the Directive in 2020.
• ***Other***	• AOK/CZ cross-border care card • CZ issued 683 cards and covered 1,258 treatment episodes for NL patients in Germany in 2020. The region of residence and treatment were not recorded, but CZ estimate 50% were border residents. This amounts to less than 1% of all care reimbursed by CZ • AOK made 639 reimbursements for care provided on the Netherlands side of the Meuse Rhine border region. Of these the majority travelled to Nijmegen (224), Vaals (138), Sittard (115), the remainder went to facilities in other cities, with numbers in double digits only. • Ostbelgien-Regelung - in 2019 Belgium issued 1,082 reimbursements under the Ostbelgien-Regelung. The most significant flow from and to Belgium

Summary of Findings- Qualitative Conditions for Cross-border Patient Mobility	Key Regional Actors	The Future	
Meuse Rhine  	Euregio Meuse-Rhine EPECS EU Prevent Euregio Rhein-Maas-Nord EMRADI University Hospitals- Maastricht, Radboud, Aachen… Insurance providers CZ, AOK Ems-Dollart region EGTC Eurodistrict PAMINA Maastricht University	Health and patient mobility data collaborative involving regional actors, health insurers, the NCPs, and other relevant stakeholders Better data means better possibilities	Patient-centred planning Underpinned by good data Cross-border shared services and economies of scale Working together – complementarity and not competition
Proximity matters in patient-centred care- for many the nearest point of care is across the border	Border regions can work on cross-border economies of scale in healthcare provision/patient mobility and provide solutions for Member States	Planning health services based on cross-border population needs	An approach informed by evidence of health inequalities
Language is a specific and crucial quality factor in a patient's decision to travel for care	Cooperation between insurers on mobility pre-dates the Directive- IZOM Card	Independent, well-coordinated information for citizens	Cross-border clinical shared services, clinical research, and translational medicine

3A Case Study 1- Meuse Rhein

3A.1 Context for Cross-border Patient Mobility in the Region

Regional Context for Strategic Cooperation to support Patient Mobility:

The context for cross-border patient mobility in the Meuse-Rhein Region is based on several decades of significant capacity development in the area of both civic institutional collaboration for cross-border health, and specific cooperation relating to specific themes within the wider spectrum of healthcare and health-related collaboration (such as patient rights, population health improvement, shared regional approaches to procurement of PPE during the COVID-19 Pandemic). Key organisations involved in this activity include Euregio Meuse-Rhine, EPECS, and EU Prevent. The Region of Meuse Rhine covers the historical cross-border province and the respective Dutch province of Limburg, the Aachen district in Germany, and the Ost Belgien region (German-speaking Community of Belgium).

A number of experienced stakeholders who have been involved in this activity over time in the region gave generously with their time and perspectives to the research which underpins this case study. In relation to this case study, there is also a body of publications which have been covered in a supplementary literature review. The body of publications available which focus on or arise from cross-border patient mobility issues in the Meuse Rhine Region is a direct indicator of the collaborative capacity in the region which has developed over the years, and which has used evidence-based working as a core principle throughout.

A key perspective offered on cross-border patient mobility, drawn from the experience in the Meuse Rhine Region, is that while it may be regarded as a 'small' issue in that the patient numbers involved may be relatively low, it is strategically very important for the EU and Member States. 30% of the EU population resides in border regions. In border regions, the administratively derived concept of 'abroad' is very close, and in many cases 'abroad' is local, and 'abroad' is where one's neighbours live, or where one accesses basic services and amenities.

It is also true that for many people living in the Meuse Rhine Region healthcare is most accessible in the neighbouring country. For people living in the Netherlands side of the border, the University Hospital in Aachen is often their nearest centre of expertise, while for some people living on the German side access to a specialist in Dusseldorf constitutes a long and arduous journey, while access to similar healthcare services in the Netherlands is a simple journey.

Organisations working in collaborative systems in and around the issue of cross-border patient mobility include **EPECS**[32] and Euregio Meuse-Rhine (EMR)[33] (at both organisational and working group level), and EUPrevent (a foundation with close links

[32] Welcome - Epecs

[33] Euregio Meuse-Rhine. Home page (euregio-mr.info)

to EMR and its constituent regional authorities). In Meuse Rhine, Citizens are also supported in accessing information about their rights (including patient rights) and entitlements by organisations such as EPECS and ZORG[34]. Euregio Rhein- Maas-Nord[35] is a distinctive Euregio structure straddling the Dutch-German border which also provides important citizens information services via a cross-border information point.

Recognising the need in the region for a more coordinated approach to healthcare access for citizens, a group of citizen activist stakeholders decided to establish EPECS to support patients' exercise of insurance rights and citizen rights in border regions. EPECS focuses on the responsibility for Member States to take care of quality principles in the context of subsidiarity. In this scenario, there is a key role for citizens as actors who call for improvement of quality of care, within a dynamic cycle of improvement of healthcare quality and access. The patient rights agenda is well established across Europe and organised within Member States. EPECS, it seems, applies the logic of a dialogue between patient citizen and state and brings this into a cross-border context where for citizens of a border region to access care and quality on the same basis as their fellow citizens in less nationally peripheral locations, a dialogue is required across state borders and with various key stakeholders. This is also the principle on which border regions engage on a wide range of development and service issues.

Cross-border cooperation in the Meuse Rhine region, relating to cross-border patient mobility issues, predates the Directive in that EPECS was established in 2007. While EPECS continues to strive for organised systems of access and information for citizens in border regions, and their rights, it has also formed an important function as a think-tank focused on health and mobility, including cross-border patient mobility issues such as those captured within this study. It has been observed by key stakeholders that despite early attempts and ongoing efforts, there is no broad European movement on patient rights. Ambitions and motivations are still strong but there is still limited ability to be effective.

The perspective remains that EPECS was set up pre-directive and diagnosed the need in the region for a more coordinated approach to healthcare access for citizens. EPECS stakeholders included Mr Decker who was instrumental in creating a legal precedent that underpinned the development of the Cross-border Healthcare Directive.

EUPrevent[36] is a place-based foundation and collaborative of 37 structural/institutional partners aimed at improving the health and quality of life of the population of the Meuse Rhine Region. It is well supported by Euregio Maas Rhein. EPECS assists EUPREVENT and the two organisations work together strategically. EUPrevent is dedicated to addressing structural social inequalities - including advocating measures to promote positive health in the cross-border region as a key component of overall competitiveness and improvement of quality of life for

[34] In de zorg / Uit de zorgen (idz-udz.eu)
[35] GrensInfoPunt – euregio rhein-maas-nord (euregio-rmn.de)
[36] Homepage - euPrevent

citizens through an approach which focuses on socio-economic rights[37]. This agenda aligns with the Province of Limburg's commitment to a social agenda.

Patient-focused collaborative clinical work transcending borders is a well-established feature of clinically-led inter-hospital innovation and cooperation in the Meuse Rhine Region. This represents a level of sophistication in cross-border healthcare cooperation in that there are strong examples of where cross-border issues are treated as a factor in clinical outcomes research as well as a factor in the daily lives of patients. Such an example is the current multicentre clinical observational study (QUIT-EMR) being carried out by UMC Maastricht and UMC Aachen to build on previous joint work on developing quality scores for cross-border acute patient transfer: this study will address the absence of established evidence-based criteria which can assess the impact of existing urgent patient transfer systems on patient outcomes[38]. A range of hospitals in the region are involved in the routine provision of care to cross-border patient catchments e.g., Radboud UMC's work with patient registries, population health improvement, and supporting cross-border translational medicine initiatives- including the work of Professor Angela Maas (also a Dutch Government UN Special Envoy for Women) in the area of women's cardiovascular health.

Additionally, the work, research, and policy advocacy of various clinicians associated with Maastricht UMC including that of Professor Jacques Scheres in relation to cross-border clinical cooperation on rare diseases is an original example of how clinical translational medicine, patient groups, and policymakers can work hand in hand to achieve outcomes for specific patient groups. Maastricht UMC has also worked in partnership with clinicians from Aachen, Liege, and Maastricht to establish a shared multidisciplinary Centre for Paediatric Surgery[39]. UMC Groningen's Cross-border Institute of Healthcare Systems and Prevention[40] represents an additional regional asset and facilitates multidisciplinary research and collaboration across a range of topics relevant for any region or population with an interest in positive health and health systems that can facilitate this.

Euregio Meuse-Rhine (EMR) has in geographical terms proved to be a significant and essential facilitator for strategic cooperation drawing on the strengths and interests of the clinical and healthcare provider community in the region. EMR has used ERDF programming as a significant leverage tool for innovation and place-based leadership responses to releasing the full socio-economic potential of the region through a holistic approach which combines the ability to act in geospatial contexts which cross

[37] EUPrevent/Euregio Meuse-Rhine (EMR) (2017) : *Exploration Implementation Plan ;* (Auth. Brigitte Van Der Zanden)

[38] Ulrich Strauch,1 Dennis C J J Bergmans,1 Joachim Habers,2 Jochen Jansen,3 Bjorn Winkens,4 Dirk J Veldman,5 Paul M H J Roekaerts,1 Stefan K Beckers6 (2016): *QUIT EMR trial: a prospective, observational, multicentre study to evaluate quality and 24 hours post38transport morbidity of interhospital transportation of critically ill patients: study protocol;* doi: 10.1136/bmjopen-2016-012861 BMJ Open; last accessed on 15.09.2021.

[39] Euregional cooperation | International Center for Pediatric Surgery (mumc.nl)

[40] Cross-border Institute of Healthcare Systems and Prevention (CBI) (umcgresearch.org)

borders, and a comprehension of the interdependency between economy, social wellbeing, and health as essential components of regional competitiveness and cohesion. EMR has adopted an EGTC structure (European Grouping for Territorial Cooperation) which is a legal mechanism conferring competency for a range of functions deemed relevant for modern, developing and integrated border regions in Europe.

The **EMRADI Project**, a collaborative of healthcare providers, patient organisations, university clinical researchers and healthcare insurers, was established by Euregio Meuse-Rhine as a key project within its programme and was funded through the EU INTERREG Programme. Euregio Meuse Rhein also has played a key role in facilitating responses at regional level during the COVID-19 public health crisis, including the accessing and sourcing of PPE for its constituent areas. Recognising the key role which data plays in cross-border cooperation and regional development- particularly that which takes place across national jurisdictional borders – EMR has sought to consolidate a regional interest and approach to statistical data collection issues including patient mobility.

"EMRaDi" stands for Euregio Meuse-Rhine Rare Diseases. The EU INTERREG VA-funded project was part of the Meuse Rhine regional INTERREG VA programme and ran for four years between October 2016 and March 2020. This project involved cross-border cooperation between health insurers, university hospitals, patient associations, and a university in the Euregio Meuse-Rhine. The project objectives were to: increase the transparency of needs and availability of services in the field of rare diseases in the Euregio Meuse-Rhine (EMR); develop EMR models for rare disease patient pathways in order to draw up patient-oriented recommendations in synergy with national and European developments; and to improve the network of healthcare providers, health insurance providers and patient organisations and raise (public) awareness of rare diseases[41].

In addition to the INTERREG and citizen-led initiatives outlined above, two of the health insurers with a strong footprint in the region have also had a significant impact on supporting access to cross-border care. Recognising the geographical needs of their region and the personal administrative burden that the Regulations and the Directive create for both patients and healthcare providers, **AOK Rhineland Hamburg (DE)** and **CZ Health Insurance (NL)** have worked together since 2000 to create a system which supports patients who need to regularly use healthcare providers on the other side of the respective border. The system thus predates the Directive, but it now addresses care which could be reimbursed under both the Directive and Regulations routes. They now operate a system of a special insurance card which allows patients to access defined healthcare services from defined healthcare providers in the neighbouring country without seeking prior authorisation. One driver for this initiative was the intention to respond in particular to the needs of patients with chronic conditions or other longer-term healthcare needs for whom seeking several prior authorisations per year was a significant burden. It also recognises that certain types of healthcare service were routinely sought over the border,

[41] EMRADI Report (2020); p5.

accordingly, putting a system in place that allows healthcare service providers to easily check the eligibility of a patient without additional administrative follow-up was seen as a significant saving in time. The system now operates on the basis of a patient-held card, like the EHIC card, and an online eligibility verification system. From the insurer perspective, the card also allows for simplification and for maintenance of local eligibility requirements, which may not be self-evident for a healthcare service provider abroad, such as a requirement for referral by a general practitioner for specialist care, which is required for patients from the Netherlands to receive care in Germany, but not vice versa.

Additional Context for Cross-border Patient Mobility:

Meuse Rhine – contribution to body of knowledge on patient mobility:

The depth of systemic, analytical, and practical work carried out by various stakeholders based in and focused on the Meuse Rhine Region has produced a significant body of literature. A review of selected sources was conducted as part of a supplementary literature review for the overall AEBR/DG SANTE study, and the following section presents perspectives which relate to the specific research focus of our study- namely cross-border patient mobility, data collection, and the stories behind the issues of mobility and reimbursement.

EMRADI has conducted some analysis of reimbursement issues for patients with rare diseases and has produced a report addressing these specific issues[42]. While this AEBR/DG SANTE Study does not specifically focus on patients with rare diseases, it is nevertheless important to reflect the evidence of how reimbursement rules may affect patients with rare diseases. From an EU Equality perspective, it is also relevant to consider how the current reimbursement and mobility patterns may include or exclude patients with disabilities, complex needs and/or complex health inequalities- these issues are direct factors in understanding the data reported on use of the Cross-border Healthcare Directive.

While the EMRADI report is a thematic publication which delivers conclusions relevant at an EU level, it is based on the experience of patients with rare diseases in the Meuse Rhine Region and of those who support their care and health insurance. It represents an important contribution to a body of research and evidence which examines more closely the subsidiary navigability of mechanisms such as the Directive and Social Security Regulation for those who may need to avail of these mechanisms for reimbursement. The work of EMRADI has originated in and been driven by stakeholders in the Meuse Rhine region in acknowledgement of the specific clinical expertise within the region and based in the region. In this sense Meuse Rhine Euregio can be said to have made a significant contribution to the wider EU debate and knowledge process regarding the full implementation of mechanisms like the

[42] EMRADI Project (2020): REPORT OF WORK PACKAGE 1 REPORT ON THE ANALYSIS OF LEGAL, FINANCIAL AND REIMBURSEMENT MECHANISMS OF RARE DISEASES FOR TREATMENT COSTS OF EMR RARE DISEASES PATIENTS.

Regulation and the Directive, for the benefit of patients and for the creation of knowledge sharing for the treatment of rare diseases.

The EMRADI Report identifies current implementation of the Directive as potentially less suited to the needs of patients with rare diseases because of the financial burden of payment 'up front' coupled with the combination of possible 'de facto' prior authorisation requirements by insurers and also the fact that patients with rare diseases often require multidisciplinary supports in order to access hospital care. Where these are not within a Member State standard reimbursement package or list this involves patients wishing to travel under the Directive incurring potential additional costs, or not travelling under the Directive because they cannot afford to bear the cost of care that is not reimbursed even if the core procedure is reimbursed. The report tentatively identifies the Social Security Regulation as a more suitable route for Rare Diseases patients in that it involves 'less administration and insecurity but is coupled with the barrier of the prior authorization requirement'[43]. The report also identifies the format and requirements of the S2 form as a potential barrier to accessing cross-border care experienced by patients with rare diseases.[44] If patients are granted authorization, 'the Regulation provides access to the treatment for the patient without advance fees, not to mention the security to be treated as a national, socially insured person of the MS providing the treatment. This provides usually more extensive benefits than the Directive 2001/24/EU[45].'

The report goes on to state that 'applying these provisions to the RDs, it becomes apparent that for RD patients experiencing multifaceted and complex limitations and disabilities regarding their physical and mental conditions, that specialized long-term care assistance cannot be accessed by means of the Directive across the border. Moreover, given that a certain proportion of RD treatment is innovative or funded by specialized schemes, accessing cross-border care may in many instances be barred by the provisions in Article 1(4), making reimbursement of cross-border care subject to the condition that this kind of care is funded usually under the social security system of that country.'[46]

The EMRADI Report also references the arrangements prior to and after January 2018 for reimbursement of cross-border patient care on the Dutch-German border- these are a) pre-2018, the IZOM Card; b) after 2018: bilateral arrangements between AOK (German health insurer) and b) after 2018, for German-speaking Belgians, the Ostbelgien Regelung[47].

Other work carried out which is relevant to the issue of reimbursements and cross-border patient mobility in the Meuse Rhine Region includes the AEBR/DG REGIO *b-solutions* project case study carried out by the Ems Dollard Region (EDR)[48]. This

[43] EMRADI Report (2020); p6.
[44] EMRADI Report (2020); p31.

[46] EMRADI Report (2020); p32.
[47] EMRADI Report (2020); p38/9.
[48] AEBR/DG REGIO Project Case Study- B Solutions Project (2021): *Transparent solutions in the border region for efficient treatment and reimbursement of medical expenses for German and Dutch*

report is concerned with obstacles to reimbursement arising from a 'lack of insight into working methods and concrete coordination with regard to the reimbursement of care costs for used care in the neighbouring country'. The study examines issues relating to the reimbursement of particular treatments and raises the issue of rehabilitative care, both of which lie beyond the scope of this study. However, the EMR case study does reference the cooperation between health insurers CZ (NL) and AOK (DE) described above, noting its benefit for insured parties and particularly in the border region.

In 2016 the Benelux Secretariat published a report on cross-border patient flows in the Benelux Union. While the data referenced in this study lies outside of the timescale for the AEBR/DG SANTE study, there are nevertheless relevant observations to note. It is understood that an updated data set for the period post-2016 may be developed. The Benelux Report indicates that international databases (e.g., Eurostat) have no comparable or complete data on cross-border patient flows between the Benelux countries or between other European countries[49]. In view of the impediment caused by the limited completeness and comparability of data in the Benelux countries, the General Secretariat of the Benelux Union has made a significant effort to provide a comprehensive and unique picture of the cross-border patient flows within the Benelux and to and from neighbouring countries France and Germany

While the Benelux report refers to patient mobility figures for the Benelux region which are pre-2016, it is significant that the Benelux Secretariat, on grounds that the geography it relates to featured increased cross-border mobility at many levels and in different contexts, decided to map patient mobility for the purposes of offering evidence to the health systems for better cooperation as a response to citizen and population needs in the area of healthcare and health services. The report as a strategic measure reflects the importance of cross-border mobility and patient mobility for the economies of the Benelux region, where the basic functionality of economies is dependent on cross-border mobility.

The Benelux report noted that a significant group of patients in the macro-region of the Benelux Union is in need of cross-border care in both planned and unplanned situations. The report sought to collate data and information which could serve to support a business case approach to improving service access on a population-based transboundary basis.

The Benelux Report noted that at the time of publication it was expected that there would be an increase in the total number of cross-border patients between the Benelux countries, France, and Germany in the future. It speculated that the Directive might influence this increase and added that in general, an increase would be expected for Belgium and Luxembourg. It also noted that in the Netherlands the

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Patients; Ems Dollard Region (EDR) and co-applicants; RA mr. Anton H.M. Bouwmeister & mr. Marlene M. Plaß, De Kempenaer Advocaten NV, Arnhem, the Netherlands.

[49] Benelux Report (2016); p5.

situation could stabilise as a result of the health insurers' policies, 'which have a strong effect on the patient flow'. [50]

The report also referred to the desirability of interoperable eHealth platforms between the Benelux countries, which would allow for sharing medical data across borders – and could also have cost-saving benefits. Respondents in the present study were asked to comment on the availability of eHealth tools such as shared access to Electronic Health Records and common format electronic discharge letters, but it seems these are not widely in operation yet (we did become aware of some localised examples between the Netherlands and Belgium in which University Hospital of Ghent is involved and this is further referenced in the final section of this report). The Benelux report also referred to the 'substantial need of high-quality information among almost all stakeholders, including patients, care providers and insurance companies' and that 'lack of information and knowledge with respect to aspects such as the quality of care abroad, the availability of care or financial aspects could result in the patient not receiving optimal care, even though it is available. The report referred to the importance of good transboundary healthcare cooperation as an important factor in both quality and cost of healthcare, the role of harmonised approaches to specialist healthcare offerings across the Benelux countries, and the 'expansion of existing and new collaborations and agreements in border regions, in view of the significant share of cross-border patient flows due to geographical proximity and cultural affinity'. The report further referred to the importance of good quality information for patients and on the role of information sharing between health insurers, noting that this needs to happen at the same pace as patient flows.

The Benelux report also highlighted the importance of data protection in advancing the quality of data available but treated this as a thing that was possible rather than an obstacle to progress- in other words, a component of high-quality approaches to digital statistical information. The report went on to emphasise the importance of 'stimulating transparent, high-quality and comprehensive data collection which is accessible and comparable for the purpose of substantiating future policy interventions and in-depth scientific research'.[51]

Another key document relevant for patient mobility in Meuse Rhine is the EUPrevent Exploration Implementation Plan (2017)[52]: In this document, EUPrevent sets out a programme of strategic regional actions aligned with regionally agreed priorities for creating a step-change in social and health conditions of the regional population. The document strongly recognises the role of structural approaches to cross-border cooperation as a vehicle for progressing such priorities. This represents a distinctive agenda in that the Meuse Rhine Region has committed visibly to an agenda to address structural health and social inequalities (associated with its strategic direction to 2025 'Limburg 2025'). This presents potential opportunities for innovative forms of collaboration which could lead to better data collection on patient mobility in an applied context of actions which are meaningful at the regional

[50] Benelux Report (2016); p10.
[51] Benelux report (2016); p11.
[52] EUPrevent/Euregio Meuse-Rhine (2017): *Exploration Implementation Plan;* (Auth: Brigitte Van Der Zanden).

and Member State level regarding the rights of patients under the Directive and also placing use of the Directive and Regulation within a structural regional approach to population health and the optimisation of limited health system resources. The EUPrevent strategy has been developed and is underpinned by ongoing collaboration with organisations such as the World Health Organisation[53].

A further recent publication of note which is relevant for Meuse Rhine and contains commentary which is useful to the overall issue of the role of the Directive in cross-border regions is the recent Maastricht University ex-ante report on the impact of the Directive on healthcare in border regions. This report highlights the capacity existing in the Meuse Rhein region also concludes that there is a lack of data on patient mobility[54].

3A.2 Member State Health Systems for the Meuse Rhine Region

This section provides information on specific provision by the health systems relevant for the case study. The European Commission's Health at A Glance report[55] is produced annually in cooperation with the OECD and the European Health Observatory for Health Systems. It provides high-quality and in-depth information on Member State population health status, risk factors, health system performance reporting, and analyses developments in overall healthcare system resourcing and administration for each Member State. In understanding the key features of the various health systems in the Member States relevant to the case study areas, the French Government's *Cleiss*[56] website also provides information fiches for countries globally which focus on information on types of healthcare provision in-country.

The Health system features for the Member States relevant to our case studies are summarised as follows:

The Belgian Health System:

In Belgium, health policy responsibilities are shared between the federal level and the federal entities (regions and communities). The federal level is responsible for regulating and funding mandatory health insurance, operating and funding hospital services.

At the level of the federated entities (regions and communities), governments are responsible for promoting health and prevention, coordinating, and collaborating between different health systems (primary or secondary care, palliative care, rehabilitation care, long-term care), implementation of funding for hospital investments. To facilitate cooperation between the federal level and regional and

[53] EUPrevent/EMR Report (2017) ; p7.
[54] Maastricht University Institute for Transnational and Euregional cross-border cooperation and mobility (ITEM): *Cross-Border Impact Assessment 2021 Dossier 4: Is the EU Patient's Rights Directive fit for providing well-functioning healthcare in cross-border regions? An ex-post assessment* (2021); p29.
[55] Country Health Profiles | Public Health (europa.eu)
[56] Centre des liaisons européennes et internationales de sécurité sociale

community governments, inter-ministerial conferences are regularly held.

The Belgian health system is based on a social insurance system characterized by solidarity, without risk selection. The organization of health services allows the therapeutic freedom of doctors, the freedom of choice of patients and the remuneration on a fee-for-service basis. Funding for the system is based on progressive direct taxation, proportional income-related social security contributions and additional financing related to the consumption of goods and services (value-added tax).

Health care is provided by public health services, liberal health professionals for outpatient care, liberal pharmacists, hospitals, and specific institutions for the elderly. Hospital care is provided either by private non-profit hospitals or by public hospitals. Most medical specialists work liberally in hospitals or in private practice (ambulatory care). GPs provide outpatient or primary care. Dentists and pharmacists generally work independently.

Health insurance covers the following benefits if they are included in the bill of refundable benefits:

- visits and consultations with general practitioners and medical specialists
- the care provided by physiotherapists
- Nursing care and home nursing services
- dental care
- childbirth
- prosthetics, carts, bandages, and implants
- hospital care
- nursing home care for the elderly
- functional rehabilitation care.

Health insurance is also used for medicines: masterful preparations, pharmaceutical specialties, and generic drugs.

The Netherlands' Health System:

The current healthcare system in the Netherlands is characterized by shared governance between government, professional organizations, and health insurers. Since 2006, the creation of a universal health insurance system has resulted in regulated competition between different health insurers and the government has retained only a supervisory and facilitator of health markets. The trend towards increasing decentralization of health and social services, particularly those for the elderly and chronically ill patients, has created a greater role for municipalities. The new universal health insurance system consists of three components: basic health care, long-term care or exceptional costs, and voluntary supplementary insurance. The health care plan is funded by contributions as well as monthly premiums paid by policyholders directly to private insurance companies.

Private health care providers and health care insurers are the primary caregivers responsible for the delivery of health services. Health care can be primarily divided into preventive care, primary care, secondary care, and long-term care. Municipalities are responsible for population health at the local level and manage primary health care and medical-social care. They must create municipal health services and are also responsible for disease prevention, promotion, and protection of health (vaccinations, health inspections, preventive screening, epidemiology, health education, mental health).

In addition, corporate occupational medicine services are responsible for the safety and prevention of diseases in the workplace.

The basic package of care, including certain benefits that all insurers must provide to all policyholders, is set by the law that determines the nature of care, their scope, and therapeutic indications. In general, it covers:

- ordinary medical care provided by general practitioners and specialists;
- maternity care
- Community care
- Nursing
- Medications
- Medical equipment
- Dental care for children (under 18)
- Hospital stays and transport of patients;
- physical therapy for chronic diseases;
- mental health medical care, including intramural monitoring by GGZ (the Dutch Institute for Mental Illness and Addiction Care) for up to three years;
- care provided by therapists such as physiotherapists and medical rehabilitation/gymnastics therapists, logo therapists and occupational therapists;
- certain paramedical care (physiotherapy, speech therapy, dietary advice).

The basic insurance in the Netherlands has two variants known as ‘natura’ insurance and ‘restitutie’ insurance, the former is lower cost. For natura insurance, the insurer makes agreements with health care providers on rates among other things. The insured person will receive full reimbursement of costs when choosing a care provider from among the contracted providers. The insured person also has the option of receiving treatment from a service provider who is not a contracting party. It does not matter whether this service provider is active in the Netherlands or abroad. However, for a non-contracting care provider, whether in the Netherlands or abroad, the reimbursement will be reduced, usually to 75% or 80% of the Dutch tariff rate. With the higher premium restitutie insurance, the insured person has free choice of service provider. Treatment by a healthcare provider who is not a

contracting party will be reimbursed up to the Dutch tariff rate, regardless of whether the treatment is in the Netherlands or abroad.

The German Health System:

A fundamental dimension of the German health system is the sharing of decision-making powers between the regions *(Länder),* the federal government and legal professional organisations. The relevant federal and regional authorities delegate their powers to social security institutions and health providers. All these players in the German health system are involved in the financing and delivery of health care covered by legal insurance schemes.

Indeed, health insurance companies, their associations and affiliated physician associations manage the financing and delivery of benefits covered by the legal health insurance system, these different associations being based on the compulsory membership of their members and the democratic choice of their representatives. In joint committees of payers (health fund associations) and providers (regional associations of doctors or dentists adhering to the legal health insurance system, or individual hospitals), legitimate actors have the duty and the right to define benefits, prices, and standards (federal level).

The German healthcare system is divided into three main areas: outpatient care, hospital care (hospital sector) and rehabilitation services. In addition, there are two complementary sectors, public health and long-term care managed by health insurance companies.

The entire population is subject to a general obligation to be affiliated with the legal health insurance plan or private health insurance. German health insurance is funded by employee and employer contributions and fully or partially covers the following benefits:

- medical care,
- dental care,
- Medicines,
- Prosthetics,
- testing and testing,
- hospital care.

3A.3 Baseline Data – Member State Data[57]

Both the Regulations and the Directive require the Member States to make reports to the European Commission annually on the use made in their jurisdictions of the two routes for reimbursing cross-border care. The data from all Member States relevant to the case studies are also contained in this report. However, the reports provided by each Member State are not always complete as explained above. The countries of the Meuse-Rhine region in particular report very limited data in the annual data collection exercises on patient mobility in 2019.

Figure 1: Reported Issue and Receipt of PDS2 Forms in 2019 for countries sharing Meuse Rhein Region

Issued = number of PDS2 reported as issued by competent MS

	Issued	Received
BE & DE	62	/
BE & NL	28	232
NL & BE	/	1006
NL & DE	/	/
DE & NL	/	/2667
DE & BE	/	93

Received = number reported as received by treating MS from competent MS treatment in treating MS

NOTE: this number is not always the same, indicating reporting variability.

/ = data not provided

0 = no reported PDS2

Table 2 – Reported reimbursements under the Directive in 2019- countries sharing the Meuse Rhein Region

	With PA	No PA		With PA	No PA	
BE to DE	0		NL to BE	n/a	/	DE to BE
BE to NL	6	/	NL to DE	n/a	/	DE to NL

/ = data not provided

0 = no reimbursements made

n/a = PA system not implemented

[57] Data report on the application of the Directive in EU countries (2019)https://ec.europa.eu/health/cross_border_care/overview_en

The Netherlands reported no data on patient mobility reimbursed under the Directive. The Netherlands NCP stated that they were not able to report on patient mobility reimbursement not requiring Prior Authorisation as this was not reported in a consistent manner by all insurers and accordingly no national aggregate data were available. The Netherlands have chosen not the implement a Prior Authorisation system under the Directive, accordingly, they had no data to report on that route of reimbursement.

The Netherlands reported an aggregate number of 2,056 PD S2 forms issued under the Regulations. The numbers were not broken down by Member State of treatment. Moreover, the numbers were only reported by a part of the competent institutions. No data were reported on the PD S2 forms received by the Netherlands.

Germany did not provide any data on patient mobility reimbursed under the Directive in 2019, nor indeed in any year since the Directive entered into force. Germany reported, similarly to the Netherlands, that aggregating data from the many insurance bodies was not possible.

Germany was unable to report any data on the issue or receipt of PDS2 forms under the Regulations.

Belgium reported only 6 cases of Prior Authorisation under the Directive, but no data were reported for reimbursements made when prior authorisation was not required. Belgium also noted the variable reporting from different insurance bodies as a hindrance to aggregating data on a national level

Belgium reported that they had issued 57 PD S2 forms for treatment in Germany and 32 for treatment in the Netherlands; and that they had received 76 PD S2s from Germany and 1,005 from the Netherlands.

The paucity of numbers reported in the annual reports was a driver for the present study, because they are not indicative of no cross-border healthcare, but rather of problems in collecting data. For all three countries, the nature of the organisation of the healthcare system through a large number of insurance bodies makes data collection difficult.

With respect to providing data on the use of the Directive, Germany has reported that:

"The German National Contact Point for Cross-Border Healthcare is part of the German Liaison Agency Health Insurance - International (DVKA). The DVKA is a department of the German National Association of Statutory Health Insurance Funds. Therefore, we have no information about the number of requests for reimbursement or the requests by countries. This information is only available at the German Statutory Health Insurance Funds and the private German Health Insurance Companies."

The Netherlands similarly stated:

"The Dutch healthcare system is implemented by private health insurers. The government relies on the accounting systems of private health insurers for this healthcare data. The data recorded in their administration systems is not identical with each insurer. These systems vary widely. As a result, it is not possible to collect aggregate data administered by the insurers."

Belgium noted along the same line that:

"Not all health insurance funds have provided data on the number of granted requests for reimbursement. Hence, we prefer not to provide you with only partial data as they do not reflect the actual situation."

With respect to the number of PD S2 forms recorded by Belgium, the report published by the European Commission noted that this is a misleading number, as it applies only to those cases of care covered by the Regulation that fall outside one of the regional agreements. As noted in that report:

"Belgium, the Netherlands, Luxembourg (BENELUX), France and Germany are involved in a large number of cooperation agreements in border areas (e.g., Ostbelgien Regelung, ZOAST etc.) where, depending on the cooperation agreement, prior authorisation often becomes a simple administrative authorisation that is granted automatically. For instance, in 2018, Belgium issued a total number of 7,815 PDs S2 under the more flexible procedure, of which 1,992 under the Ostbelgien-Regelung.

Additional data collated and published by the EU in 2019 on Member State social security co-ordination based on statistical reports[58] provide the following overview which is also relevant as giving context for patient mobility in the region:

- Persons insured in Germany but reside in another Member State -- data not available
- Persons reside in Germany but were insured in another Member State -- data not available
- PD S2 forms were issued by Germany for care in another Member State -- data not available
- 100% German population has an EHIC
- 233.626 were insured in the Netherlands but reside in another Member State
- 39,277persons reside in the Netherlands but were insured in another Member State
- 3,044 forms were issued by the Netherlands for care in another Member State
- 63.1% NL population has an EHIC
- 118,732were insured in Belgium but reside in another Member State
- 159,367persons reside in Belgium but were insured in another Member State

[58] Germany - https://op.europa.eu/en/publication-detail/-/publication/375b244e-0bec-11ec-adb1-01aa75ed71a; Netherlands - https://op.europa.eu/en/publication-detail/-/publication/43adf961-0a02-11ec-b5d3-01aa75ed71a1; Belgium - https://op.europa.eu/en/publication-detail/-/publication/6a0964d4-0bfb-11ec-adb1-01aa75ed71a1

- 208 S2 forms were issued by Belgium for care in another Member State
- 35.6% Belgian population has an EHIC

3A.4 Data Discovery Findings – What is known about patient mobility in the Meuse Rhine Region?

Given the limited data on cross-border reported to the European Commission by the NCPs responsible also for the Meuse Rhine Region, we conducted both interviews and roundtable meetings with key stakeholders in the region to establish if more quantitative or qualitative data could be brought to light to establish the nature and quantity of cross-border care in the region. Amongst the stakeholders, we interviewed representatives from the German insurer AOK Rhineland Hamburg, and the Dutch insurer CZ, who have implemented a joint insurance card which facilitates access to care in the Netherlands for patients from Germany living in the border region, and for Dutch patients seeking care on the German side of the border. The impetus for the card, known as eGCI in Germany and Zorgcard in the Netherlands, was to enable access to care that is either geographically or temporally closer for the patient. It can only be used for specialist care in hospitals or outpatient facilities, and certain categories of care are excluded, for example, rehabilitation, which is handled very differently in the Netherlands and Germany.

The representatives from the National Contact Points reiterated the comments quoted above, confirming that they did not have access to granular data which is collected by each individual insurance organisation. The insurers indicated that it would be possible to obtain detailed data on patient mobility in the border regions by extracting this data from client files, but indicated that detailed data would be accessible only once a legal basis for re-examining the data for research purposes under GDPR had been established and that furthermore, such data would need to be pseudonymised. The insurers were able therefore to share only relatively limited data on patient mobility using the eGCI/Zorgpass, but the data they were able to provide indicate that there is good interest in cross-border care in the border region populations.

Germany

The respondent from AOK provided basic data on the use of the eGCI card in 2019, which provide a good picture of the extent of its use but given further detail on the type of care accessed. AOK noted that the data to which they have access are limited to the fields which are collected in the S2 form procedure, which are used also in the eGCI card system. They comprise:

- Start and end of the care episode
- insurer
- In-patient or ambulatory, pharmacy, dentist or ‘other’
- Cost of intervention
- Name and date of birth of patient

The data provided by AOK Rhineland Hamburg show that in 2019 some 639

reimbursements were made to patients living in the German EUREGIO region who received care in the Netherlands border region. Of these the majority travelled to Nijmegen (224), Vaals (138), Sittard (115), the remainder went to facilities in other cities, with numbers in double digits only.

AOK Rhineland Hamburg was not able to provide more detailed data on the use of the card at this time. However, the representatives reiterated the importance of the card and noted that it represents a lifeline for some patients who would have very difficult cross-country journeys to access care in Germany, which can be easily accessed in the Netherlands. Although the overall numbers for cross-border care may be small in comparison to the total use of social insurance-based healthcare, its value to people in border regions should not be underestimated. It was noted however that since the adoption of the eGCI card, The Directive and S2 routes are very rarely used in the Meuse Rhine region between Germany and the Netherlands.

It was noted by AOK that in the PDS2 form the care provider (e.g., hospital) location and care provided are not recorded, accordingly for care reimbursed under the Regulations it is not possible to identify border region care accessed by home patients, thus the data reported above on the use of the eGCI card would not necessarily be available for other border regions. However, the German insurers do collect data on location of care provision and residence of the patient where care is provided to a foreign patient and where reimbursement has to be sought from the foreign insurer (or insurer in another jurisdiction). Accordingly, it would be possible for German insurers to provide quite good data on the patients received in Germany from another Member State, however, using such data for research purposes would have to be permitted on the basis of a GDPR provision before such research could be undertaken. While it would be interesting to have a better oversight of the sort of care provided in the border regions, it was not thought that the AOK at national level would see value in undertaking this data analysis at present. It was noted that the cost of such data collection outweighed the benefit that the data might provide even though it was acknowledged that it could be very interesting to know more about the sort of patient care that is delivered in the region across borders.

Netherlands

The respondent from CZ noted similarly that some further data might be accessible if data protection requirements were met, but similarly to Germany noted that for the Netherlands no data would be available on the nature of care beyond the diagnosis-related group code (DGR) since Dutch law does not allow insurers to collect more detailed diagnostic information. However, with respect to simple reimbursement numbers, the CZ was able to offer some data on reimbursements made in 2020:

- 852 episodes of care in DE were reimbursed under the Directive, but the region of residence or care could not be specified.
- 89 PD S2 under the Regulation were issued for patients to travel to Germany
- 683 patients were issued with the Zorgpass, and 1,258 care episodes were received by Dutch patients in Germany.

On the numbers for care reimbursed under the Directive, the respondent was of the opinion that some 50% could be patients living in the border region, but this was her estimation only. On the use of the card, the respondent noted also that the card is available to all patients insured in the Netherlands and could therefore also have

been used by patients from outside the border region. The respondent also commented that in total less than 1% of all reimbursements made by CZ are for care in another country. This small number does not, however, imply that cross-border care does not have a high level of importance for patients living in the border region. However, it was noted that the general practitioners in the region are well aware of the possibility of sending patients for specialist care in Germany and are likely to be the main conduit of information about such care.

For the Netherlands, it was also noted that where cross-border care is sought, the preferred route is a prior agreement system such as the CZ/AOK card. The pre-payment requirement of the Directive was identified as a significant disincentive to patients, while prior authorisation under the Regulation was rarely given because almost all care is available in a reasonable time in the Netherlands.

3A.5 Qualitative Research Findings

Mobility and Reimbursement Issues

The fact remains that data on cross-border care is limited. Despite collaboration to facilitate specific cross-border collaborative working in relation to patient care and clinical innovation, at a whole-systems level there is little unity of purpose in relation to the collection of data on patient mobility. The primary sources of patient mobility data are financial in nature, derived from records of financial transactions as a primary indicator evidencing patient mobility.

Our qualitative findings in relation to how data are currently collected on patient mobility are contained in the following key points arising from the in-depth engagement we had with NCPs, insurance providers and other stakeholders with insight into data collection processes relevant for patient mobility in the Meuse Rhine region, many of which echo the comments provided by NCPs in the reports made to the European Commission as quoted in section 3A.3 above.

- Collection of data by health insurance providers in the Netherlands is not an obligation and data are not shared with the NCP, it is, therefore, difficult to motivate insurers to collect detailed data.
- In Belgium, the health insurance providers annually transfer data at end of April, and this is consolidated in the Ministry before being shared with NCPs. But because not all Health insurance providers (HIC) report data in the same way, which results in some data being lost in the final aggregated data sets.
- All data in Germany, Netherlands and Belgium are collected at a local level. National Contact Points can give feedback on data quality to health insurance providers but cannot enforce or prescribe data quality issues. The willingness of health insurance providers to respond to special requests for additional data, such as in the case of a pilot or experimental project was noted- however, it was also noted that the challenge is then to mainstream this data provision once a pilot phase is over. In some cases, NCPs advise patients to contact their health insurance provider for better information about where they can access cross-border care.

- It was indicated that German healthcare insurers do not collect data on whether a cross-border patient treatment journey or episode is with prior authorisation or without prior authorisation, a suggested reason being that healthcare insurers may largely have dispensed with the prior authorisation process and the patients go where they want to go.
- As regards private sector healthcare insurers in Germany, and for reasons related to commercial competition, information on contracts or bilateral agreements between specific healthcare providers and health insurers is not known at NCP level.
- The issue of digital health data systems in different jurisdictions, not interfacing was identified as a key obstacle to accessing and sharing data. Where independent healthcare insurers are involved, companies use different data capture templates within digitalised systems, adding to challenges in the consistency of data capture in the first place. There are however some localized examples that we became aware of between Belgium and the Netherlands of where digital exchange of clinical data is working across borders on a localized basis and we refer to this in our final chapter of the report.
- Specific data are collected in connection with the implementation of the *Ostbelgien Regelung* (OBR), a specific mechanism that has been introduced since 2018 (replacing the IZOM Card which was an overarching predecessor for all citizens of the Meuse Rhine Region). This serves the German-speaking community of Belgium (East Belgium). The data are collected for the purposes of accountability and monitoring of the OBR's implementation.

Ostbelgien Regelung (OBR)

- Very good data are available on cross-border patient mobility which occurs within the framework of the *Ostbelgien Regelung* (OBR), an agreement designed to support the German-speaking community of Belgium, resident in East Belgium, in accessing patient care across the border in defined geographical areas of Germany, close to the border. The OBR provides specifically for circumstances in which care accessed under the Directive may be complemented by clinically necessary care under the S2 provision (such as consecutive hospitalisation beyond initial procedure, and medical imaging services). Where the S2 is used, detailed data are available at the point of capture i.e., the OBR requires key details of the case to be provided on the S2 to inform prior authorisation. This detailed data capture at source enables the translation of this data into information on the implementation of the OBR which covers which hospitals, type of reimbursement, the age profile of the patient group, new/review attendance figures. It was noted that psychiatric care is one of the specialty areas in which patients cross the border for- particularly given that Belgian healthcare providers cannot always offer German-speaking healthcare professionals.
- In the context of the OBR, the NCP also asks health care providers to signal

where there are problems, particularly noting that where there are problems in border areas, these are the results of interaction between two different healthcare systems, and it is important that these problems are known if they are to be addressed. While not directly related to the focus of this study on Directive data, some issues around specific issues of reimbursement of pharmaceutical costs under cross-border prescription arrangements are cited as an example of how different regimes can concretely impact patients (e.g. reimbursement of pharmaceutical costs from cross-border prescriptions is done automatically in Germany as a default, until a decision is taken not to reimburse- whereas in Belgium a decision must be actively taken to reimburse).

- Currently the data for the OBR is derived from an administrative approach to organising care which uses the S2 form in some cases (as an 'administrative S2'- i.e., no need to check undue delay criterion) and the Directive in others.
- While the data relating to cross-border patient mobility under the OBR is detailed for the purposes of overall monitoring of the implementation of the OBR, there are concerns about whether this would be continued in the context of a mainstreamed arrangement which might replace the OBR.

The issue of mainstreaming detailed data collection and sharing, rather than it being an exception and under special circumstances, remains a challenge. In this context, it was noted that the data quality for implementation of the *Ostbelgien Regelung* is excellent and consistently detailed, but this is because the agreement itself requires and commits to detailed monitoring of its implementation. While the Ostbelgien Regelung was extended for a three-year period pending development of mainstreaming/stabilisation arrangements to ensure its objectives become part of normal business, there were doubts expressed about whether mainstreaming of the arrangements currently provided for under the OBR would include continued provision of a high level of data and detail. In Belgium, additional complications in control of the quality of data collected may arise with the decentralisation of healthcare competencies to regions

Additional Observations

This section highlights a range of additional observations derived from qualitative research interactions including interviews and focus groups. Findings are presented aligned with the key questions which informed enquiry in our focus groups, and which are themselves aligned with the overall research protocols used throughout our research. While the following findings may not specifically relate to the issue of data collection processes, they do provide qualitative information as important context for understanding current data on the implementation of the Directive and may provide useful context for the development of approaches in the future which can lead to better quality data on the Directive in a fashion that eliminates gaps of the nature which currently exist.

What influences a patient's choice/decision to travel for care?

- In the Netherlands patients rely on their general practitioner and insurer for information which then influences their decision to travel (or not). For planned care, the normal procedure is to make contact with your insurer first, and the insurer will authorise the care if there is a prior agreement in place with the provider. However, for patients paying the higher rate 'restitutie' insurance described in section 3A.2 will find access to care easier, given that they have an entitlement to the full Dutch social rate reimbursement for care abroad, whereas those paying the lower premium will receive a reduced reimbursement, usually at 75-80% of the Dutch social tariff. Therefore, full access to choice as derived from the Directive is dependent on financial means of the patient, as reflected in their choice of healthcare insurance premium.

- Whether reimbursement is at the full national rate or lower, a major difficulty for patients deciding whether to travel for care under the Directive is the payment up front. People prefer to go under the Regulation and not under Directive as there is uncertainty about the level and scope of reimbursement

- One advantage of the Directive is that prior authorisation may be required only for certain types of care, however many patients try to obtain prior agreement from the insurer because they want certainty on the financial issue, even where the prior notification system provided for in the Directive has not been formally adopted by the Member State. So, the idea of PA creates an arbitrary influence of financial considerations on the matter of access to the care- while there may be no clinical PA, there is a de facto financially driven system of prior authorisation in operation which may not take clinical needs into account in individual cases.

- Those from the Meuse Rhine Region who travel for care under the Directive- are those that can afford it, those who are really well informed, and those who have a pre-directive relationship with a clinician on the other side of the border and who wish to keep travelling for continuity of care.

- The impact on the patient of the Directive's pre-financing requirement, in regard to certain types of planned care- for example, cancer treatment- was highlighted in focus group discussions also. It was suggested that the process for accessing care under the Directive has a potentially negative effect on the concept of a patient-centred care pathway which is at the heart of contemporary clinical treatment philosophy and service integration principles.

Language and Care Quality as a Determinant Factor in Patient Decision to Travel for Care:

- Patients from the Netherlands travel easily to Belgium, Germany and vice versa. However, this is a cross-border area with three languages- and where a language minority- for example, the East Belgium population- prefer to receive care in their first language which is German. The issue of language/settlement patterns and the geographical location of the point-of-

care for health services cannot be examined or catered for in isolation from each other in Meuse Rhine (and is a general theme in any border region which is not monolingual). The example was given that someone from Limburg accessing care in Liege may make sense on paper, but in reality, the fact that services in Liege are French or Flemish-speaking and the patient from Limburg may be German-speaking presents a practical issue for a key feature of high-quality clinical care (and safety) which is effective patient/clinician communication. It was further highlighted that Wallonia does not show as large an uptake of cross-border care possibilities.

- Language is a major factor in inpatient mobility and should be seen as a care quality issue: While the Belgian health system offers a wide range of care in-country, language is an issue for Ostbelgians. Ostbelgians are more oriented to accessing care in Germany because of the language- for example, for some Ostbelgians, Aachen is a preferred point of care as clinicians are German-speaking, over Liege where clinicians are more likely to be Flemish or French-speaking. Equally, language is also a barrier for French-speaking patients of Liege province as their nearest point of care 'abroad' is likely to be German-speaking rather than French-speaking.

- The reasons that a patient chooses to travel may not be solely based on whether they can access a particular type of care in-country: the quality issues around that care- particularly where language is concerned- are a major factor in mobility decisions.

- For organisations interested in the overall issue of cross-border healthcare cooperation, and population health improvement in border regions (including access to the most proximate point of relevant care), there is a lack of available data on which to reflect and plan. There is a further need to improve the knowledge of what is already happening as regards patient mobility and the impact it has on the development of cross-border systems of care, and the impact it has on particular patient groups within the population- including those with rare diseases.

How do citizens in the region get their information on cross-border healthcare opportunities?

The primary care Doctor (General Practitioner) is often the first point of contact for a patient. GPs are therefore influential in the decision as to where a patient goes for care. Insurance companies are obliged to facilitate a patient's request for care but will restrict this to the terms of agreements they have with specific providers or networks of providers. GPs sometimes have agreements with care providers across the border. Insurance companies are more likely to say no to a GP referral than a secondary care specialist referral to a CB care provider. Patients in the Netherlands can choose their insurance provider on an annual basis. NL law does not incentivise its providers to offer CB options to customers.

NCPs information is provided on request rather than on a pro-active basis; what is available for patients is ultimately a restricted version of free movement. EPECS and other organisations on the ground in the region may be able to assist with more

creative approaches to the dissemination of information for patients and there is some networking on a European basis between organisations with an interest in citizen access to this kind of information. As regards cross-border patient mobility, it is not only a matter of providing information on reimbursement options: citizens also need to be informed about quality and risk management in relation to hospital-acquired infections.

What role do health insurance providers play in facilitating cross-border patient mobility in the region?

Insurers participating in the Meuse Rhine discussions shown to have flexibility and be prepared to engage in innovation for the benefit of the client base. The advantage of a regional collaborative already established, with a track record of collaboration on both practical and policy-related aspects of cross-border healthcare and health, should not be underestimated and forms an important baseline of capacity for future actions at the level of the region but with participation and input from the Member State on the one hand, and the insurance industry on the other hand, through a place-based approach.

As regards the role of insurers, it was clarified that AOK (Germany) and CZ (Netherlands) have a working arrangement which applies to patient mobility in certain circumstances in the Meuse Rhine region. As context, it was outlined that Germany has three cross-border treatment agreements in three border regions. One, for Germany/Ostbelgien, works on the basis that there is a good baseline health service in Ostbelgien, with the presence of University Hospitals. The S2 option introduced care beyond the border, and attempts were made at digitalisation of systems to support the management of patient mobility. There is, however, little patient mobility flow from Germany to Belgium even though German-speaking healthcare options exist in the Ostbelgien region.

The question of the relative benefits and scope of the old IZOM Karte scheme, to the more recent Ostbelgien Regelung, arose throughout discussions. So too did the issue of the advance financing by the patient of care to be reimbursed under the Directive. It was emphasised that the patient who travels must be sure that all costs can be reimbursed, including the associated costs of travelling for care- the more ill the patient is, the less able they are (and the less reasonable it is to expect them) to carry out the level of administration required at a personal level in order to access their entitlement under the Directive. In this context, the insurers AOK and CZ have adopted the eGCI card scheme to ease the use of the Regulation to facilitate a greater proportion of cross-border patient mobility; in the circumstances where the Directive is used, there can also be direct invoicing between the healthcare provider and the insurer- relieving the patient of the burden of administration- but again this is a local and specific aspect of joint working and focuses on patient and clinician enablement rather than on creation of a streamlined data set.

Respondents provided a perspective on the technical cooperation of insurers prior to the arrival of the Directive. The IZOM card arrangement was in effect a 'cashless' system, based on a history of fluid cooperation between insurers such as AOK/other German insurers, CZ/VHZ in NL and Belgian insurers such as MC. At the end of a year, parties to the IZOM scheme reckoned and settled any differences in outgoings

through insurer-to-insurer recoupment arrangements. Subsequently, the Directive was introduced and following this there was a shift by some healthcare systems in the region to using the terms of the Directive for reimbursement rather than what were perceived by respondents to be the more patient-friendly terms of the IZOM card scheme. The advent of the Directive also saw the establishment of the *Ostbelgien Regelung* which is more limited than was the scope of the IZOM scheme.

NL Insurance principles are that treatment is free at the point of care, therefore insurance providers prefer their clients to use contracted providers and support that preference by reducing the rate of reimbursement if a non-contracted provider is used.

In Germany, there are different kinds of insurance policies governing different types and levels of care. Rehabilitation and long-term care require a different kind of policy from that which might only cover emergency and routine care. The difference in costing models for care is an issue intrinsically linked to the issue of insurance reimbursement. For example, the German costing model for recharging of patient care costs includes apportioned overhead costs but the Belgian costing model does not- so a DRG Cost of Hip Operation in DE is €5000 but only €3000 in Belgium. The cost of care in Germany is, therefore, higher in terms of unit cost per operation. A patient can be offered the opportunity to see a clinical lead or consultant (again additional cost) but a Dutch insurer may not cover this.

Aachen is a major centre of care. Many Germans who live in NL are insured in NL but prefer to access care in DE and via their first language. CZ is the main insurer with AOK in MR and the other one is VGZ.

Why are there gaps in data on cross-border patient mobility?

The following points provide an indication of various understandings among stakeholders as to why gaps exist:

- The template of the S2 form is observed as having a direct influence on the nature of data captured through existing processes for implementation of the Directive. For the Member State, it is in theory possible to say how many S2 forms were issued and received, but as noted above, Germany and Netherlands do not aggregate these data at national level.
- There is no current arrangement for any electronic care records in the region's Member States to interface in a GDPR-compliant fashion with public statistical data collection processes.
- In the Netherlands the NCP is not involved in collecting data- the Ministry of Health collects some data from Dutch health insurance companies for the purpose of reporting under the Directive and Regulation, but the Ministry cannot currently fully influence the extent and format of this data or the approach to data capture taken by individual health insurance provider organisations. For this to change would require further legislation at national

level to require insurance providers to share data with the Ministry.

- The State does not have the legal authority to force health insurance companies to provide data in either Germany or the Netherlands. In this context, Border regions may be the place to pilot new forms of cross-border healthcare access and cooperation. This is particularly so because the border is not in the mind of the patient population or those institutional actors in border regions in the same way as it might be in the minds of centralised administration.
- Health insurers hold the richest data on CBHC. We should connect the statistical offices of the three governments and create a regional dashboard for patient and population health stats. Info between primary and secondary care does not integrate well in the Netherlands.

What are the future possibilities for cross-border patient mobility in the region?

Municipalities have good relations and communication in the cross-border region. How we do things at the border is via tailor-made solutions. There is case-based collaboration at hospital level and this works well- also in respect of emergency care. There is political desire at the level of certain municipalities at the border, to ensure that bilateral solutions are put in place and acknowledged as a necessary complement to the Directive and its meaning on the ground at borders.

Politically, there is support for cross-border patient mobility at the level of the region. The question was raised as to whether, in the wake of the COVID-19 pandemic, there should be examination of the scope for clinician mobility rather than patient mobility within a particular territory. There may be reservations in the healthcare system as to the impact of increased use of the Directive on hospital catchments and that there may be a perception that this could lead to hospitals losing a catchment population- which is necessary in order for particular specialties to be maintained in a geographical location. This issue represents the tension between the principle of individual choice available under the Directive and a system of geographical healthcare provision which does not necessarily consider the Directive as a strategic enabler of improved provision to cross-border patient catchments and populations. The point has been made at political level in the region that the patient must come first, and that patients do not wish to wait for services. The realities of regional housing markets can also mean that patients- by necessity- live on the other side of a border- this is a particular feature of cross-border urban agglomerations and is a well-known factor in the development of the cross-border shared services agenda.

The general view is that the IZOM card scheme worked well- it involved the use of prior authorisation via the S2 form. There was some debate on the merits of IZOM versus those of the Ostbelgien Regelung, as to how patients have benefitted under the two arrangements. It was felt that there could be further and more detailed promotion of cross-border patient care opportunities by the NCP and other parties involved in the insurance or provision of care. As regards the availability of data, there is a lot of information but data collection in a format that could be used for planning purposes – or for wider discussion purposes in the region- is not a high priority for insurers.

While there is a digital primary care patient record and a secondary care patient

record, there is no interface between these systems at present in NL. The ideal patient experience is no borders between primary and secondary care. There are ongoing issues with professional accreditation of clinicians on a cross-border basis. We need shared medical education.

Women's health should be a greater priority throughout the region. There is a history of attempted cross-border care to benefit cross-border patient catchment. Consistency of care and access through clinical cooperation is an area of interest. Results of a pilot action and study on cross-border clinical cooperation in the provision of gynaecological services to women in the Meuse Rhine region will be published in the Journal of Gynaecology. More could be done around specialist care for women. Women are interested in their health and care delivery must suit them- there is a case for gender-specific approaches to best quality and combined offerings of care in border regions, which can both meet and be supported by cross-border patient catchments. Euroregions and other cross-border structures, including EGTCs, are ripe for sharing best practice amongst networks of clinicians.

There is an opportunity to create greater connections between primary care and specialised medicine to empower the patient with a central role. Clinical population groups exist in border areas and there will be more work done by clinicians in the Meuse Rhine region in the coming years.

Planned care - which empowers the patient to take a preventative approach to health and to promote their own wellbeing based on best practice knowledge and clinical guidance and support- is a crucial factor in how well emergency medicine copes with pressures and can help to control pressures on unscheduled care.

Long Term Conditions are common in the Meuse Rhine region- linked with lower income, socio-economic stress, and poorer health outcomes.

Transboundary working in the medical sense is hugely important and innovation is on the border at MR region- the beginnings of a population health-led CB health collaboration are there. There are barriers to progress in this presented by existing reimbursement conditions, and the fact that certain types of care are not considered specialist as they are delivered by GPs- therefore not defined as specialist or 'Facharzt' care; so while a patient may wish to access a specialist service in primary care, this may not be viewed as eligible for reimbursement out of country, because of interpretive rules of insurers. Understanding the principle of moving specialist care out of hospital settings and into community and primary care settings is crucial for things to move on- integrated care and moving care closer to the patient -in primary care and in community settings- are the future and those financing cross-border care need to understand this. Some commissioning models also, therefore, impact whether CBC and CBPM are possible to their fullest extent. The payment system for doctors is not orientated towards multidisciplinary working around the patient. These issues, while clinical, prevent progress in collaboration. The system works against innovation. Innovation goes slowly and must be multidisciplinary. Payments are currently only organised along the lines of main diagnosis. If you start to reimburse and reward innovation by Doctors- e.g., review and scrutiny of false diagnoses, if the patient keeps going to ED with the same issue, then you start to influence innovation for better patient outcomes. Bonus Malus system in the payment. Often the advisors in the insurers are clinical specialists and make advice that supports their interests.

Looking at population health risk factors and organising care and innovation systems around these- especially at borders where population health inequalities tend to exist- is a humanitarian direction towards positive health for all in WHO terms.

While there is a question as to the extent to which health promotion can be facilitated by the Directive, there is a role for the Directive in overall health and recovery of systems in a post-pandemic environment. The issue arose of the role of planned care management in the context of the recovery of health systems post-COVID-19, as waiting lists are much longer due to cancellation of routine planned care services in order to focus health systems resources on the crisis of unscheduled care. The need for recovery post-COVID-19 of health systems presents another future collaboration opportunity which would need to be underpinned by effective data sharing and capture in order to be effective- that is, the planned reduction of waiting lists and clearing of planned care backlogs created by the pandemic. It was suggested that if a planned and systematic/collaborative approach were to be taken in border regions to addressing waiting lists post-COVID-19, and if other countries were prepared to participate, then the pandemic could be shown in future to have stimulated innovation in shared and collaborative approaches to healthcare access in border regions.

There may be further scope to develop and test the concept of cross-border patient catchments as a way of utilising the Directive in a positive way to benefit both patients, assist cost-effectiveness for Member States through the adoption of cross-border shared services models, and maintain high-quality care for a border population, working on the basis of spatial complementarity within a cross-border territory.

In Meuse Rhine there is a specific need and opportunity to develop a shared territorial approach between hospitals to investment and procurement of hospital equipment, based on shared catchments and viability models which take into account that hospitals in border regions can also service wider in-country catchments- this point should be particularly taken into account within Member States if exploring opportunities for patients- not just those in border regions- to access essential care closer to home- whether that is in-country or across the nearest border.

What would better data do and who is interested?

The issue of health inequalities between the five sub-regions constituting the Meuse-Rhein region arose during the research. The example was cited of life expectancy in Limburgh being currently 2.7 years longer than that in the province of Liege. The point was made that without data it is impossible to identify such issues and that collecting data makes sense.

As regards future possibilities, it was suggested that a basic principle for all future collaborative approaches to healthcare and resultant data collection on patient mobility must put the patient at the centre of the process and attempt to reduce or eliminate the degree to which there is a burden on the patient for complicated administrative follow-up to ensure recoupment of funds outlaid in order to access the care.

There are possibilities for collaboration in the region which do not specifically relate to planned care- for example, the development of a Mobile Paediatric ICU service between Belgium, Netherlands, and Germany for the region- which should be underpinned by good quality and effective data collection as a service planning and performance monitoring tool.

Participants felt that it would be useful if there were a movement across Europe to define optimal positive health in physical, social, and emotional terms, determined by the degree to which the patient is enabled by health systems to self-manage and take a preventative approach to health issues. The definition of positive health involves seeing the patient is empowered, as the active expert in their own health and needs, and to organise services and entitlements to care on this paradigm- rather than seeing the patient simply as a consumer of healthcare. The collection of data as a key source of evidence for implementing whole-system approaches to positive health, with the assistance of tools which enable mobility such as the financial reimbursement mechanisms of the Regulation and the Directive, would be an essential component of a holistic place-based approach to health- particularly but not exclusively that in border regions.

This issue was seen as particularly important to shaping future collaboration on patient mobility because border areas have traditionally experienced population health inequalities- the Directive can have a positive role in addressing some of the more structural issues underlying these inequalities in border regions. It can also provide clarity and have a positive impact for patients with rare diseases- however, more can be done around patient self-empowerment and supporting the patient in their social setting to stay as well as possible.

The Meuse Rhine region has a health working group comprising representatives of hospitals and patient organisations. This working party could act as regards better data and explore interaction with the Member States on a collaborative basis. The insurers, in this context, will also play a crucial role in the success of collaborations which also led to or deploy improved approaches or models for better data collections. Better data would improve the quality of interventions for a population of 4-5 million people in this region, as regards both resilience, health promotion and prevention, treatment, and recovery. The issue of data-informed population health planning is crucial for this region in that there is a considerable section of the population of Meuse Rhine which experiences low-income levels- and the well-documented impact on physical and mental health that this creates.

Further data exploration- in the context of creating a more comprehensive data set for population health and also cross-border patient mobility- should also focus on mapping the totality of treatment contracts which exist in the Meuse Rhine region.

Cross-border patient mobility data should be of interest to public health agencies in the general context of having full data on the totality of a Member State population for which they have responsibility.

Civic authorities played a significant role in the region in responding to the COVID-19 crisis, through activities such as the sourcing of large supplies of PPE. As well as making emergency planning and response easier to target in the future and

contribute to post-pandemic resilience, better data on patient mobility can – with the right stakeholders involved- both enable and influence better provision of planned care on a coordinated basis in border regions.

Impact of COVID-19 on cross-border patient mobility in the region

The survey results for the Meuse- Rhein Region highlighted a general perception that the impact of COVID-19 had increased patient mobility for unscheduled care, had inhibited some travel for planned care (although for a full picture of which specific lockdown periods this may relate to, the 2020/2021 figures will provide more detail). Participants also highlighted that COVID-19 had led to new forms of cross-border cooperation related to healthcare. The Euregio Meuse-Rhine provided significant leadership in the sourcing and logistics required for supply of PPE to healthcare providers and others in the initial stages of the pandemic and this role may highlight the potential benefits of shared territorial approaches to healthcare-related purchasing including that of capital equipment for core clinical services in the region.

As regards the impact of COVID-19 on patient mobility, there has been close cooperation in the region and while insurance providers do not have all requests for reimbursement as a data set, it is assumed that the pandemic period will show a drop in planned care figures and a rise in unscheduled care provision. There will be specific information on the nature of patient mobility in the context of COVID-19 and it is expected that this may show a rise in reimbursement for the costs of COVID-19 testing. Insurers reported an increase in information requests from people who needed COVID-19 tests or vaccines as well as ICU treatment on the basis of patient transfer. It was verbally reported by respondents that 140,000 planned operations were cancelled in the Netherlands part of the region due to COVID-19 and that the Ministry is determined to clear the backlog. The pandemic presented an exacerbation of the routine challenges to populations in border regions associated with differences in public health restrictions in different jurisdictions. Public health services data sharing in the context of COVID-19 has been a huge challenge and perhaps exploring this- in context of the lessons learned through the Pandemic about the general health benefits to citizens of effective data sharing- may be an interesting area for future collaboration.

The pandemic has highlighted the benefits of data sharing, and the disadvantages – for citizens and public health management- of inadequate or non-existent arrangements for public health data sharing. In this context, there should be a role for public health agencies in future data-sharing arrangements- for the purposes of both operational planning, and for the purposes of statistical analysis which can inform public service and health service planning and delivery in border regions.

The pandemic, through restrictions on general cross-border mobility determined by different rulings on mobility which were made for public health reasons, also affected carers and their mobility. If there were better data perhaps better decisions could be made.

3A.6 Analysis

There appears to be good capacity for collaborative approaches to improving the quality of data and the consistency of data capture and collection in that the key actors in patient mobility data are in a series of collaborative working relationships which have developed over time.

More can be done to improve patient access to care pathways in a way which takes account of care quality issues including language, multidisciplinary supports for patients with complex needs, and the development of population-based planned healthcare services which are constructed on the basis of shared catchments and a transboundary model of financial viability that has the potential to benefit not only border regional populations but a wider section of the overall population within Member States. Stakeholders expressed a desire that future patient mobility should take account of the patient experience and that patient journey mapping should be a methodological tool that is used in the context of future cooperation.

Further work can be done through cooperation between NCPs in the Meuse Rhine Region and civic actors such as the Euregio Maas Rhein and EPECS/EU Prevent in making citizens' information accessible in an independent way and not via the health insurers only (as appears to be currently the case). By default, health insurers have become the arbiters of whether a patient can travel or not and there is a stage before this which must involve the patient having access to independent information, which is accessible, assisted through local awareness-raising and contact points, and which can support the patient making a decision based on full awareness of options.

The arrangements by insurers of direct reimbursement to healthcare providers take some of the pre-financing burden off patients. However, this does not compensate for the impact on patients of the pre-financing requirement of the Directive and the role that the pre-financing requirement may play in low uptake of the Directive.

The Directive cannot be made responsible for the delivery of all possible innovations in cross-border care access. Instead, it is a supporting mechanism which enables the patient journey from a resourcing point of view. Better data on uptake of the Directive could be achieved in the context of healthcare cooperation in the Meuse Rhine region which specifically explores the Directive as an asset and a tool for solving emerging challenges such as planned care and post-COVID-19 waiting lists.

Some capacity building amongst public decision makers is necessary in relation to the role which data can play in helping to achieve objectives which relate to the needs of the region. Such capacity building - creating a better understanding of how good data can help - is likely to build support for investment in data collection as a key component of further health-related and healthcare-related collaboration- of which patient mobility levels are an indicator.

A question was also raised as to the understanding of the basis on which the Dutch NCP can request data on patient mobility from insurance providers. Some clarification of this may be useful in the context of future collaborative approaches to

data collection.[59]

3A.7 Conclusions and Case-Specific Recommendations

From AEBR's overview drawn from our research, it is clear that collaborative cross-border working in Meuse Rhine on the issues of health/healthcare and patient mobility (including insurers) is of a sufficient critical mass to fall into three of the essential categories for successful cross-border healthcare cooperation that is placed in a wider context of population health, wellbeing, and citizens' rights. These are, first, territorial cooperation involving civic and democratic institutions; secondly, sectoral cooperation between clinical healthcare providers, and thirdly, sectoral cooperation between healthcare commissioners or financers (in this case, health insurance providers).

This leadership of clinicians based in the region, combined with the dedicated work of other actors in the civic and social fields, is critical to the region's emergence as a potential laboratory of future-focused healthcare collaboration and model of excellence for population health-based cross-border patient mobility located within a context of need and design-led service configurations.

The role of civic organisations and democratic governance in articulation of needs and advocacy for resources in border regions is vital to enabling civil society to input to a cycle of improvement for positive health outcomes. The role of civic institutions also optimises the potential of enabling mechanisms for cross-border patient mobility to both facilitate mobility or influence service improvement within Member States. Better data is a central component of any future successful collaboration at the level of the region. Furthermore, the region can offer central governments innovative opportunities for working with subnational actors to address and solve problems in ways which form expression of the EU integration values and of cohesion policy.

Overall, there is capacity in the region for significant clinical cooperation to meet the needs of cross-border patient populations. This collaboration has been clinically led (rather than financially or administratively led) and represents a significant area of clinical innovation which can benefit cross-border catchments but also provide national centres of excellence which can benefit whole country populations.

The building blocks exist for a 'super-pilot' on cross-border health and mobility which can address the following objectives: -

A) **Creation of a health promotion and a population health-led approach to planning services including cross-border shared services** which can be partially supported through the utilization of patient mobility mechanisms such as directive/social security regulation, and which can also be supported by collaborative working around mainstream or corporate healthcare administrative and operational budgets such as that which includes joint procurement of capital equipment for hospitals. This work should also support a regional platform for specialty clinicians to work together on

[59] https://wetten.overheid.nl/BWBR0020078/2021-07-01#Hoofdstuk5

further exploration of shared clinical services and joint working on epidemiological priority needs of the regional population.

B) **Clinical shared services, clinical research and translational** medicine based on cross-border patient catchments and population health prevalent needs

C) **Coordinated information and access mechanisms** for citizens to access care on the basis of clinical need and quality (including closer to home) rather than on the basis of financial expediency

D) **Establishment of a data collaborative involving regional actors, health insurers, the NCPs, and other relevant stakeholders**: towards development of a population health surveillance data dashboard and data collection arrangement which advances the objectives of EUPrevent in promoting positive health, and which can inform specific interventions to facilitate patient flow and mobility, as well as providing better and more comprehensive data on patient mobility under the Directive. Identifying a template for data collection should be based on shared objectives and may usefully draw on the template developed by AEBR in connection with this project. Future data collection should also include specific consideration of regional data mobility connected with rare diseases, and also on the use/uptake of patient mobility mechanisms by people with disabilities).

3B Case Study 2: Grand Est (FR)- Luxembourg

3B Case Study Table of Contents- Grand Est (FR)-Luxembourg

Grand Est (FR)- Luxembourg	Summary of Findings- Key aspects of cross-border patient mobility **Key players:** Franco-Belgian Observatory on Health (OFBS), Zones Organisées d'Accès aux Soins Transfrontaliers (ZOAST) , TRISAN trinational partnership **Sources of information** Responses to questionnaire, interviews with TRISAN and OFBS representatives, 2020 Annual Report on Directive, 2020 Annual Report on Regulations (both citing 2019 data); representatives of Luxembourg NCP and patient advisory group
***Who** are the key players?* • ***Who** uses care?* • ***Who** informs care?*	• Mobility is heavily influenced by more general mobility between France and Luxemburg for professional and family reasons. Luxembourg's workforce was 43.7% cross-border workers in 2020. This includes both those living in a border region, and others such as the Portuguese who represent more than 11% of the Luxembourg workforce. • Although not a focus of the case study, the Grand Est region in France issued more PDS2 for care in Germany than in Luxembourg (109 sent to Germany 92 to Luxembourg) • Luxembourg has a dedicated body for providing information to patients which is publicly funded but is not a government body. France has been trialling an extensive patient information portal to guide French citizens through the use of the Regulations and the Directive.
***What** cross-border care is accessed?* • ***What** types of care are accessed?* • ***What** influences patient mobility?*	• A high number of border region workers use care in the two countries where they live and work, this is often funded under the designated cross-border worker mechanism in the regulations (PDA1) • Some disease areas are a particular focus of mobility, notably chemotherapy, which accounted for the highest proportion of publicly funded care in Luxembourg for French patients, followed by dialysis. For patients travelling from France Germany, the most common care provided was for lymphoedema. • The fact that many doctors in Luxembourg have undertaken some or all of their training in France is reported to account for close professional relationships and referral for care in France, in particular in oncology and other complex diseases. • Well-developed relationships between hospitals, established relationships between healthcare professionals often driven by training across several countries, rather than dedicated payment systems such as ZOAST operating between FR and BE.
How** is cross-care reimbursed?* • ***Regulation	France and Luxembourg report the greatest use of both the Regulation. Luxembourg accounts for 33% and France for 11% of all PDS2 issued in 2019. The French data collection system for cross-border care is complex and does not enable a clear distinction between different mechanisms, and in some cases does not report bi-lateral agreement use, such as ZOAST. Current records show the number of people spending 1 night or more in a hospital in another EU country, no further specification of the data is available. This skews data on the use of the Directive which in 2019 showed France as making over 60% of all reported reimbursements for care under the Directive. **Regulations** - **France issued** 2,613 PD S2s in 2019 of which 140 were for care in Luxembourg (Luxembourg reported receiving 188); **Luxemburg issued** 11,765 PDS2s of which 1,477 were for care in France (France reported receiving (571).

• ***Directive***	Directive - **France reimbursed** 13,235 care episodes in Luxembourg not requiring PA and 138 with PA; Luxembourg was not able to provide data on reimbursements for care not requiring PA and reported 490 care reimbursement with PA ZOAST – The ZOAST agreement exists between France and Belgium and accounts for a very large percentage of the total use of the Regulation, Belgium reported receiving 21,310 PDS2 from France, but noted that most of these were under the ZOAST agreements which France had not recorded at PDS2s issued, not counting the ZOAST issues within the standard PDS2s. Data provided for the Grand Est region for care provided abroad for patients insured in one of the ten municipalities of the Grand Est region showed that of 338 PDS2 issued 92 were for Luxembourg, of which 43 were for chemotherapy and 17 for dialysis. The majority of patients from Grand Est travelling to receive care went to Germany (in total 109 PDS2 were issued).

Summary of Findings- Qualitative Conditions for Cross-border Patient Mobility	Key Actors	The Future	
Grand Est (FR) - Luxembourg 	Region Grand-Est (FR) Luxembourg Hospitals Federation Wider Grande Region stakeholders OFBS Agence Régional de Santé (ARS) Grande Region working groups on cross-border patient mobility Insurers and hospitals- ZOASTS	Health and patient mobility data collaborative involving regional actors, healthcare providers, health insurers, the NCPs, and other relevant stakeholders Better data means better possibilities Region Grand Est (FR) and Grande Region – Roadmap to Health- Integrated Health Observatory- how can this benefit the wider Grande Region	Patient-centred planning Spatial planning approach to cross-border shared services and economies of scale – integrating health data to the 'Smart Regions' agenda Working together – complementarity and not competition Including health and patient mobility in European Digital Innovation Hubs
Proximity matters in patient-centred care- for many the nearest point of care is across the border	Border regions can work on cross-border economies of scale in healthcare provision/patient mobility and provide solutions for Member States	Consistency of approach and legal templates for bilateral cooperation	From experiment to 'business as usual'- Involving the right people at the right level of institutional decision making
Language is a specific and crucial quality factor in a patient's decision to travel for care	Cooperation between insurers on mobility pre-dates the Directive- ZOASTS	Independent, well-coordinated information for citizens	TRISAN Guide de Mobilite – model of best practice

3B Case Study 2 - Grand Est (FR) - Luxembourg

3B.1 Context for Cross-border Patient Mobility in the Region

The focus for this case study is specifically the factors underlying patient mobility data relating to the Grand Est (France) region/Luxembourg, and cross-border patient mobility relating to this area. The researchers acknowledge that historically the 'Grand Est' region is located within a wider cross-border functional area known as the Grand Region and that there are both overlaps and some distinctions in the findings which relate to Grand Est (France). It is also important to acknowledge the intrinsically cross-border nature of the workforce in the region- particularly the Luxembourg workforce which is heavily dependent on frontier workers as is the Luxembourg healthcare system itself.[60]

The Grande Region, as a macro-region, covers a wider territory including Saarland, Lorraine, Luxembourg, Rhineland-Palatinate, Wallonia and the rest of the French Community of Belgium, and also the German-speaking Community of Belgium.

The Grand Est (France) Region is a border region within this wider territory, is unique as a French region in that it is bordered by four other countries including three EU Member States (Germany, Belgium, Luxembourg, and Switzerland). It contains the nine French administrative Departments of Ardennes, Aube, European Community of Alsace, Haute-Marne, Marne, Meurthe-et-Moselle, Meuse, Moselle, Vosges. 5,559,051 inhabitants or 8.4% of the French population[61].

The main technical actors involved in cross-border patient mobility, and in cross-border cooperation in general, are a range of insurers from the different countries in the Grande Region- these are a mixture of private, social, and public, depending on the Member State and respective healthcare governance regimes.

In Grand Est (and indeed the wider Grande Region), there is also strong civic leadership from the regional authorities along the border and a desire to drive improvements in cross-border health cooperation. Strong, place-based civic and political leadership is recognised as a crucial feature of current and future cohesion policy, particularly in relation to territorial cooperation as a central tenet of cohesion. The EU institutional focus on the role of cross-border regions as key features and 'laboratories' for delivery on the overall EU integration and cohesion agenda recognises the role of integrative and symbiotic processes at borders. At the heart of this agenda is the need for strong regions which can support sectoral actors to deepen and systematise cohesion- which also involves the removal and amelioration of obstacles to cross-border cohesion and mobility within the EU.

[60] Dr Philippe, Turk, Luxembourg Hospital Federation: Presentation to 44th World Hospital Congress (Barcelona, 2021).
[61] Presentation of the territory - GrandEst

There is a strong legacy of healthcare cooperation, and regional political and civic support for healthcare cooperation in the wider Grande Region also- putting cross-border cooperation at the centre of developing services in border areas, not just as a self-development axis for specific border territories. The context for cross-border patient mobility in Grand Est needs to be understood in the wider context of a body of work which has been undertaken by various stakeholders in the area of cross-border health and healthcare cooperation/patient mobility since the 1990s at least. Much of this work has been driven by interpretations of citizenship within a European context as well as a national context, and the patient rights agenda as it navigates the various levels of administrative governance and jurisdictional authority which overlap in the Grand Region.

Historically, a reflection of the level of capacity for collaborative strategic analysis of patient access and mobility issues, the Grand Region has had two interagency and cross-border working groups dealing with health. One of these groups is a collection of the social partners in the region with an interest or remit in facilitating patient mobility, including the Mutualités (social models of health insurance originating in the third sector); the other working group consists of representatives of public health authorities including Health Ministry representatives and- in the case of Germany- representatives of Federal (Bundesländer) Health Departments. Additional organisations providing crucial observatory input to this process over time are the Franco-Belgian Observatory on Health (OFBS) and TRISAN[62].

The Franco-Belgian Observatory on Health (OFBS)[63] represents an early model of European best practice in the area of cross-border healthcare access, which combines an evidence-based approach with practical action to deliver results. The OFBS has worked intensively over several decades since the early 1990s to facilitate actors to work together to create the necessary conditions for patients to access cross-border care. In recognition of the essential involvement of not only health insurers but healthcare providers themselves, the OFBS has provided seminal leadership on models such as the Zones Organisées d'Accès aux Soins Transfrontaliers (ZOAST) agreements. These represent micro-territorial cross-border agreements between insurers and providers to serve a specific population. There are currently seven ZOASTs in place along the Franco-Belgian border. Notably, all but one of these pre-date the establishment of the Directive. Our research focused on the kind of data on patient mobility which is typically collected under these arrangements and this is further examined in section 3B.4 of this case study chapter. The work carried out by key actors such as Henri Lewalle, an independent cross-border health expert in the region (with a previous connection to OFBS), and those who continue to maintain the OFBS -and stimulate the practical demonstration of what is possible when stakeholders work together to facilitate cross-border patient mobility- cannot be underestimated for its overall contribution to the cross-border health agenda at EU level. This work has also formed a crucial baseline to the intellectual capital and level of understanding which is now expressed through initiatives such as the Grand Est

[62] english - Trisan - Trinationales Kompetenzzentrum für Ihre Gesundheitsprojekte
[63] OFBS | Observatoire Franco-Belge de la Santé

Health Roadmap in addressing the next steps required to consolidate and deliver a strong, future-proofed legacy of efforts to support cross-border health and facilitate patient mobility in the Grande Region as a whole.

TRISAN[64] is a dynamic tri-national partnership and centre of excellence to facilitate and navigate cross-border health issues in the Upper Rhein region- a subregion of the wider Grande Region. TRISAN has contributed significantly to the understanding of patient mobility and the development of tools which can assist citizens and patients, as well as providing intellectual leadership for evidence-based healthcare cooperation in the region. Of particular significance to the topic of cross-border patient mobility is the current work of TRISAN specialists Eddie Pradier and Anne Dusapp in development of a detailed patient mobility guide which is likely to prove a model with great potential for not only replication across other cross-border health catchments across the EU, but generalisation for any border regional citizens wishing to cross the border for care along the specific borders covered by TRISAN.

Grand Est, as a political and administrative region covering the totality of the Franco-German border as well as bordering on Belgium, Luxembourg, and Switzerland, shows strong emerging leadership in proactively addressing cross-border strategic issues for health, which are orientated to the needs of its population. In respect of health, the region has visibly committed to not only technical cooperation in the area of health services (noting that some basic issues such as coordination, synergy and strategic location of services benefit whole countries) but has also committed to improvement of the health of the regional population, through the December 2020 adoption of a health roadmap for the region for the period 2021-27.[65] In the health roadmap, the public leadership of Grand Est region recognises health of the regional population as a central element of land use planning – which in itself is a crucial element of regional competitiveness, quality of life and cohesion. In this sense, better cooperation- not only between health services but also involving healthcare professionals, is recognised as a key pathway to improving the health and quality of life of the Grand Est Region.

The Grand Est Health Roadmap represents a practical and whole-systems approach to effective population-based and needs-based planning for health service access and provision. The Roadmap recognises the unique position of Grand Est as a border territory and commits to working with neighbouring jurisdictions to create responses to provision and strategic planning which are designed according to SMART objectives and which also address the necessary structural factors required for successful delivery to the region's population. The Roadmap contains specific commitments to the issue of cross-border patient mobility in the region, noting that it has a significant workforce which is mobile across borders and that cross-border

[64] TRISAN - Trinationales Kompetenzzentrum für Ihre Gesundheitsprojekte - Trisan - Trinationales Kompetenzzentrum für Ihre Gesundheitsprojekte

[65] Region Grand Est (2020) : *FEUILLE DE ROUTE SANTÉ 2021-2027 L'ambition d'une meilleure qualité de vie dans le Grand Est (Grand Est Health Roadmap)*

mobility is a core feature of the rhythm of life for the region. The Roadmap- published at the height of the COVID-19 Pandemic Crisis, represents an up-to-date strategy which takes account of the learning from prior experience of the pandemic and highlights the fact that cross-border interdependencies have been highlighted acutely in the context of the pandemic.

Crucially for this study and for the implementation potential of recommendations, the Grand Est Region Health Roadmap acknowledges the work carried out by various actors and working groups across the Grande Region and proposes a consolidation of this work into a dynamic regional observatory model.

Taking into account this work and also the urgency for coordinated approaches to health created by the COVID-19 Pandemic, the Grand Est Health Roadmap includes a clear objective to establish a comprehensive observatory for health which will complement and augment the work of existing working groups and organisations with subsidiary remits within the wider territory. The observatory will combine both epidemiological data for the population with observational data on issues like mobility, and link this with healthcare offerings in a prospective fashion that is forward-looking and orientated for delivery and action. This observatory will be aimed at providing an evidence base and the necessary strategic governance links to relevant actors, so that evidence can directly inform the adaptation and development of healthcare offerings in the region and actions by all actors[66].

The proposed measure in the Grand Est Roadmap represents cutting-edge best practice in place-based governance for cross-border health which integrates the work of health sector actors with the governance and advocacy processes intrinsic to democratic and civic institutions. The issue of health is a subset of overall regional functionality and this integrative thinking is central to post-pandemic recovery and resilience as well as facilitative of the necessary enabling measures for cross-border cooperation which require political and civic administrative support and which actors in the health sector may have found difficult to achieve without the support of democratic decision-making institutions who are concerned with governance of a territory.

In a practical and general sense, the following qualitative feedback points summarised from our participative research also characterise the context for patient mobility relevant to the Grand Est Region:

- Mobility in the Grande Region has been focused on the needs of disease or condition-based patient groups including renal disease management, maternity (Ardennes)- but need to go further than speciality-specific hospital agreements. It is important to build out from the territory for health agreement signed in 2005 which provided the potential for specialty/patient group accords.

- The strategic advocacy focus on healthcare and cross-border patient mobility has historically been on the needs of the individual in the context of patient rights and social rights and has emphasized these issues.

[66] Grand Est Health Roadmap; pp103-106.

- It is understood from responses to our initial questionnaire that data is collected in the region through a wide range of actors and systems, some based on particular agreements, some on particular localities, but the formats, indicators and reporting time frame vary significantly making comparison or aggregation difficult.

- The majority of cross-border patient mobility in the Grande Region is facilitated under the reimbursement mechanisms of the ZOAST agreements, which is a localized implementation of the Regulations PD S2, however, the standard PD S2 route is also well used in the region and the Directive route is also used

- A number of bilateral agreements also exist, some of which are disease-specific. Some of which have emerged due to connections between referring clinicians.

- The Grande Region working group is planning a mapping exercise to ascertain how many cooperation agreements currently exist between healthcare providers and different authorities. There are different stakeholders and configurations within agreements, partially due to differences in governance requirements within each part of the wider territory. There is a demand from public authorities to have a clearer view of the landscape for patient mobility- and this will allow for the generation of better information for patients.

- Cross-border issues are not a high priority for public authorities but good practice needs to be standardized in the content of bilateral agreements. While there are variations in cooperation arrangements for cross-border care- and this is a natural thing along different parts of the border (and the same thing cannot be done along each border in the Grande Region) things should be simplified for patients.

- The region also has a high number of cross-border workers who are entitled to healthcare across the border as frontier workers under the PD A1.

- In particular, for women living in Belgium and working in Luxembourg, maternity care in Luxembourg is seen as better. However, there are challenges when it comes to postnatal care or paediatric neonatal care- in such cases, it is vital to ensure that the child is with the mother.

- The French national insurer has 4 bilateral arrangements in place, with Belgium, Germany, Switzerland, and Spain. For patient mobility from France to Luxembourg, there is no specific bilateral agreement and all mobility is reimbursed via the Directive or the Regulation. In some cases, it is possible to distinguish where the Regulation or the Directive have been used but this depends on the channel through which the information has come.

- There has been significant analysis conducted in the region since the 1990s around the obstacles to patient mobility. Appropriate involvement is now required, of the right stakeholders from key organisations with the necessary decision-making authority from those organisations, to deliver the change

and sustain/embed the solutions.

- Where there are bilaterals and accords for specific care, a few hospitals account for the majority of patient journeys-A closer analysis of this hospital held data could be interesting for future studies.

Referenced also in the Meuse Rhine case study, the 2016 Benelux Report also holds observations and recommendations relevant for the Grand Est (France) region:

In 2016 the Benelux Secretariat published a report on cross-border patient flows in the Benelux Union. While the data referenced in this study lies outside of the timescale for the AEBR/DG SANTE study, there are nevertheless relevant observations to note. It is understood that an updated data set for the period post-2016 may be developed. The Benelux Report indicates that international databases (e.g., Eurostat) have no comparable or complete data on cross-border patient flows between the Benelux countries or between other European countries[67]. In view of the impediment caused by the limited completeness and comparability of data in the Benelux countries, the General Secretariat of the Benelux Union has made a significant effort to provide a comprehensive and unique picture of the cross-border patient flows within the Benelux and to and from neighbouring countries France and Germany

While this report refers to patient mobility figures for the Benelux region which are pre-2016, it is significant that the Benelux Secretariat, on grounds that the geography it relates to featured increased cross-border mobility at many levels and in different contexts, decided to map patient mobility for the purposes of offering evidence to the health systems for better cooperation as a response to citizen and population needs in the area of healthcare and health services:

The Benelux report noted that a significant group of patients in the macro-region of the Benelux Union is in need of cross-border care in both planned and unplanned situations. The results of the study show a 'business case' in support of future policy investments, which may improve the accessibility and quality of cross-border healthcare.

3B.2 Member State Health Systems

This section provides information on specific provision by the health systems relevant for the case study. The European Commission's Health at A Glance report[68] is produced annually in cooperation with the OECD and the European Health Observatory for Health Systems. It provides high-quality and in-depth information on Member State population health status, risk factors, health system performance reporting, and analyses developments in overall healthcare system resourcing and administration for each Member State. In understanding the key features of the various health systems in the Member States relevant to the case study areas, the

[67] Benelux Report (2016) ; p5.

[68] Country Health Profiles | Public Health (europa.eu)

French Government's *Cleiss*[69] website also provides information fiches for countries globally which focus on information on types of healthcare provision in-country.

The Health system features for the Member States relevant to our case studies are summarised as follows:

The French Health System:

Under the French health care system, care is provided at various types of facilities: private practices for non-hospital care, healthcare facilities for hospital-based care, health and social care, and residential facilities for "vulnerable" elderly or disabled persons. It is grounded in the patient's and resident's freedom of choice: each patient is free to choose his/her primary care physician ("*médecin traitant*"), may directly access a medical specialist, health care facility, or residential facility, either in the public or the private sector.

France's public health insurance system *L'Assurance Maladie* covers the following types of care if they appear on the official list of reimbursable care:

- hospital-based care and treatments in public or private health care, rehabilitation, or physical therapy facilities,
- non-hospital-based care provided by general practitioners, specialists, dentists, and midwives,
- doctor-prescribed diagnostic tests and care provided by medical laboratories and allied health professionals (nurses, physical therapists, speech therapists, etc.);
- prescribed pharmaceuticals, medical devices, and prosthetics which appear on the official lists of reimbursable products;
- prescribed medical transportation.

The Health System in Luxembourg:

Based on the values of solidarity, universal accessibility and fair treatment, Luxembourg's health system is characterized by:

- universal coverage of the population through compulsory health and dependency insurance,
- a mandatory agreement for providers authorised to practice a profession or health activity and the obligation for the provider to comply with rates set with the National Health Fund (CNS),
- a leading liberal exercise in medicine with the attending physician as the initiator of all benefits that can be claimed by health insurance,
- the patient's free choice of the provider and direct access to the specialist physician,

[69] Centre des liaisons européennes et internationales de sécurité sociale

- planning for the hospital and pharmaceutical sector,
- fairness of treatment of providers (legal or physical persons), regardless of their status.

Funding for the health system is provided, on the one hand, by social contributions levied on wages and contributions paid by employers and, on the other hand, by a contribution from the State. The government's contribution is mainly based on general tax revenues.

The resources needed to finance the health system consist mainly of contributions, except for the financing of maternity benefits and family leave allowances that are borne by the state.

The National Health Fund (NSC) sets the overall budget for maternity insurance each year for the following year. The budget is accompanied by a multi-year program that provides a forward-looking outlook for the financial evolution of health insurance. It negotiates annual budgets with hospitals for operating costs. It enters into agreements with the various professional groups, relating to the rates of benefits, in order to settle the relationship between health insurance and health care providers practising legally in Luxembourg.

As for the financing of dependency insurance, all assets and retirees pay a special contribution on all their professional income (salary, pension, and annuity) and on all income from the estate. This contribution is supplemented by a contribution from the State, as well as a contribution from the electricity sector.

Health care is organized around several actors:

- Doctors,
- medical-social centres,
- Hospitals,
- childcare,
- Pharmacies,
- help and care facilities,
- home care networks.

GPs provide primary care, which is mainly about prevention and less specialized diagnosis and treatment of diseases, in the form of consultations. Health care facilities such as hospitals, as well as medical practices of medical specialists, provide secondary care. This is mainly counselling, diagnosis, treatment, and specialized care. Help and care facilities or home care networks provide rehabilitation care, more often after hospitalization.

3B.3 Baseline Data – Member State Data[70]

The reported data on patient mobility between France and Luxembourg show a significant amount of patient movement under both the Directive and the Regulations. However, the reports provided by both countries show that these data do not clearly differentiate between the reimbursement mechanism.

The French NCP has made clear that the data on patient mobility from France to Luxembourg reported as being reimbursed under the Directive also includes most of the cases of patient mobility reimbursed under the Regulations, with only a few cases excluded where the category of care clearly falls under the Regulations. This exclusion is based on certain types of clinical intervention that are always reimbursed under the Regulation and therefore excluded from the number of reported cross-border care reimbursements which are aggregated nationally without differentiation.

The data reported by Luxembourg are similarly conflated, because the authorization procedure in Luxembourg treats requests concerning the Regulations and the Directive equally in a first step, only later establishing which scheme is to be used, and the data available at NCP level collect only the first step data. As a result of this Luxemburg chose not to report data on use of the Directive for care without Prior Authorisation, as the NCP believed the numbers quoted could be misleading.

Table 1 – Issue and receipt of PDS2 forms in 2019- France and Luxembourg

	Issued	Received
FR & LU	140	188
LU & FR	1,477	571

Issued = number of PDS2 reported as issued by competent MS
Received = number reported as received by treating MS from competent MS treatment in treating MS
NOTE: this number is not always the same, indicating reporting variability.
/ = data not provided
0 = no reported PDS2

Looking at the Report on the Regulations, Luxemburg reported issuing 11,765 PD S2s, of which 1,477 were for care in France; France reported issuing 3,867 PD S2s of which 194 were for care in Luxembourg.

[70] Data report on the application of the Directive in EU countries (2019)https://ec.europa.eu/health/cross_border_care/overview_en

Table 2 Reimbursements under the Directive reported in 2019 – France and Luxembourg

	With PA	No PA
FR to LU	138	13235
LU to FR	490	/

/ = data not provided
0 = no reimbursements made
n/a = PA system not implemented

Around three out of four prior authorisations in 2019 have been authorised to receive planned cross-border healthcare in an EU-15 Member State. The most prominent flows of PDs S2 take place from France (competent Member State) to Belgium (Member State of treatment), from Luxembourg to Germany, from Germany to Austria, from Germany to Switzerland, from Austria to Germany, from Luxembourg to Belgium, and from Belgium to Luxembourg. As the Commission's report notes, "This makes it clear there is a very concentrated use of planned cross-border healthcare within a limited number of EU-15 Member States (mostly based on bilateral agreements on cross-border collaboration) (LU, DE, AT, BE, NL and FR) and Switzerland."[71]

Furthermore, the authors of the Commission's 2020 report (reporting on mobility in 2019 on the use of the Regulations estimate that France issued 25,000 S2 forms in 2019. This estimate is based on the fact that France reported issuing 3,867 PDS2 forms, but Belgium reported receiving 21,310 from France. The disparity arose because Belgium included the PDS2 forms issues under ZOAST, while France did not.

Additional data published by the European Union on social security co-ordination according to statistical reports (2019)[72], while not specifically on patient mobility, provides additional context for patient mobility for the case study region:

- persons insured in France but reside in another Member State - data not available
- persons reside in France but were insured in another Member State - data not available
- 2,631 S2 forms were issued by France for care in another Member State
- 9.8% French population has an EHIC

[71] Coordination of social security systems at a glance 2020 Statistical Report, p.14
[72] Luxembourg- https://op.europa.eu/en/publication-detail/-/publication/6e68f5ce-0a26-11ec-adb1-01aa75ed71a1; France- https://op.europa.eu/en/publication-detail/-/publication/9291a261-0bfa-11ec-adb1-01aa75ed71a1

- 232,733 were insured in Luxembourg but reside in another Member State
- 5,473 persons reside in Luxembourg but were insured in another Member
- State
- 11,765S2 forms were issued by Luxembourg for care in another Member State
- 76.8% of Luxembourg population has an EHIC

3B.4 Data Discovery Findings- What is known about patient mobility in the case study region?

Despite significant interest in cross-border care with the French and Luxembourgish NCPs and interaction with several local stakeholders in both countries, it was not possible to establish complete data on cross-border care. Pockets of data were available, but no common data collection protocols were followed in order to allow systematic comparisons to be made.

France: the respondents reiterated that in France data on cross-border care are not easily divided between the different payment routes or regions. The fact that this is not ideal has been acknowledged and new processes are now being put in place to allow data to be collected in a more systematic manner. A trial of new systematic data collection will begin in the Grand Est Region in 2022, with new data sets to be ready for analysis, including for submission to the European Commission in2023.

At present the insurers record only the numbers of persons spending one or more nights in a hospital in another EU country, whether this is reimbursed under the Directive or the Regulation is not recorded. One reason for this is that the application of the Regulation on France is defined by a national law[73] which defines very clearly the ten categories of care which may be reimbursed under the Regulation, these are all interventions requiring at least one night in hospital or:

- Care requiring the expensive equipment as defined in Article R. 6122-26 of the Public Health Code;
- Cardiology interventions using medical imaging by an endovascular route
- Endovascular interventions in neuroradiology;
- Ophthalmological intervention on the lens with or vitrectomy or any other ophthalmological surgery;
- The liberation of the carpal tunnel and other superficial nerves in ambulatory as well as other surgical interventions on the hand
- Treatment of chronic renal insufficiency by extrarenal purification;
- Treatment of cancer;

[73] Arrêté du 27 mai 2014 établissant la liste des soins hors de France nécessitant le recours à des infrastructures ou équipements médicaux hautement spécialisés et coûteux https://www.legifrance.gouv.fr/loda/id/JORFTEXT000029054348 accessed on 24 September 2021

- Examination of the genetic characteristics of a person or identification of a person by genetic fingerprinting for medical purposes;
- Clinical and biological care for medically assisted procreation and biological activities for prenatal diagnosis

Only care requiring at least one night in hospital or one of the nine types of care above may be reimbursed under the Regulation, all other care is reimbursed under the Directive, noting that reimbursement will be at the same rate as the care would be reimbursed in France, and access to care remains subject to the same rules as in France, such as referral by a general practitioner for certain treatments.

France also operates a system of prior authorisation for certain types of care reimbursed under the Directive, these include:

- Dentofacial orthopaedic treatment (ODF);
- Physiotherapy in the context of rehabilitation situations
- Certain laboratory tests and analyses;
- Certain cholesterol-lowering drugs;
- Certain medical appliances
- Certain medical equipment.

In some cases, prior authorisation may also be given for the inclusion of patient transport costs into the fees which may be reimbursed. The procedure for such prior authorisations depends on the treating physician who provides a form which must be completed and sent to the insurer for assessment. The insurer must provide a response within 15 days from receipt of the request, if no response is received the authorisation is granted by default. The data reported annually to the European Commission by the National Contact Point are aggregate in the manner outlined above. However, a respondent from the Direction Régionale du Service Médical Grand Est provided more detailed numbers of cross-border mobility reimbursements made. These were reported as reimbursements under the Regulations, but the respondent noted that only each individual local insurance office (caisse primaire) is able to provide information on the modality of reimbursement and that these data are not collated.

The data provided by the Direction Régionale du Service Médical Grand Est to this study on the ten municipalities which span the Grand Est region show how many reimbursements had been issued for care in seven countries, as well as the type of care that was reimbursed. The data relates to claims made between 1 January and 30 September 2021. The data do not show if the care was provided in a hospital or other care provider in the border region of the receiving country, but it does indicate that the patients were living in a department which is in the border region, although in some cases the patient may be living some distance from the border. An excerpt of the data received from France shows the following numbers for cross-border care from the Grand Est region in France to Luxembourg- most flow comes from the two départements (municipalities) directly bordering Luxemburg: Moselle, and Meurthe et Moselle.

	Luxembourg	
Ardennes	0	
Aube	0	
Marne	0	
Haute Marne	0	
Meurthe et Moselle	42	(28 for chemotherapy)
Meuse	2	
Moselle	47	(13 for chemotherapy, 17 for dialysis
Bas Rhin	0	
Haut Rhin	0	
Vosges	1	
all departments	92	

Luxembourg: Luxembourg has only one insurance body, CNS, but like the insurance bodies in France this body collects data only on the cases of care reimbursed, it does not distinguish between those reimbursed under the Directive or the Regulation. In addition to the Directive and the Regulation Luxembourg has adopted several bi-lateral agreements such as the ZOAST agreements and also agreements with some hospitals in Germany (in Rhineland-Palatinate) through which the hospital may issue an invoice directly to CNS.

Luxembourg is also working on a new agreement which will provide for cross-border care between France and Luxembourg, including ambulances and hospital care (Accord Cadre de Co-opération Transfrontalière). The administrative agreements have been reached but are not yet operational. They will not only facilitate easier cross-border care but will also allow for better data collection, which is much needed.

The new agreement will allow Luxembourgers from anywhere in the country to seek treatment anywhere in France. For the Luxembourgers, it is not a border region agreement, but for French citizens, it will be available to those living in the Grand Est Region. The new agreement has been developed with a particular focus on serving the needs of frontier workers.

Although no hard number data on care between Luxembourg and France were available, the respondents reported that cross-border care from Luxembourg fell into patterns. The comments were based on their long experience of processing claims and information requests, rather than systematic data analysis. A number of people travel from Luxembourg to Portugal, but this is likely to be for family reasons. In the Grand Est Region travel from Luxembourg to France was most frequently for access to specialist care, notably cancer care. It was noted also that many doctors in Luxembourg had trained in France and often retained links with colleagues in France

to whom they refer for diagnostic tests and investigations. Luxembourg also experiences some use of its maternity services by women living on the French side of the border, this is primarily because several maternity units in France have closed and not because the Luxembourg units are the nearest.

In Luxembourg, the Directive remains the main stated mechanism for planned care. However, the Regulations are often more convenient for patients because the patient does not need to pay upfront and because in certain circumstances, it can include costs like transport.

Discussions with French and Luxembourg NCPs included consideration of root data capture points within existing arrangements for documentation and reimbursement. There are some plans to try and address this so that disaggregation of data between the two mechanisms for mobility. Specifically, there are plans to make changes to the data recording system in LU to support better differentiation between Regulation or Directive reimbursements which would allow for better data capture and disaggregation.

There is positive interest in the issue of improving data collection on patient mobility among actors involved. Discussion included interest from the French NCP in looking at Belgian data collection processes in this regard. The issue of data on prior authorisations requested and refused was also discussed, as were various options which could possibly be implemented in the monitoring and counting of requests for information as compared to actual mobility figures. France is planning 4 conventions with Belgium, Luxembourg, Germany, and Czechia to define the rules for the provision of healthcare services for patients across the respective borders (already in place for Belgium).

3B.5 Qualitative Research Findings

Mobility and Reimbursement Issues

The models of reimbursement in France are complex[74] and do not clearly distinguish between the Regulations and the Directive route the way they do in other countries. France provides that when a patient has paid for care up-front, despite having obtained a PDS2 authorisation, the patient can then choose to ask for reimbursement at the French tariff and will receive that within 30 days. The patient can also ask for reimbursement at the rate charged in the treating country but may then have to wait several months because the insurer will need to obtain the applicable rate from the treatment provider. If the patient does not make a choice the rate at the treatment provider will be reimbursed, that is in accordance with the Regulations.

Additional Observations

[74] A worked example for care provided in Germany: https://www.trisan.org/fileadmin/Patientenleitfaden/FR/35FR-ResFR-AffFR-SoinDE__CEAM-S2-S3_.pdf

This section highlights a range of additional observations derived from qualitative research interactions including interviews and focus groups. Findings are presented aligned with the key questions which informed enquiry in our focus groups, and which are themselves aligned with the overall research protocols used throughout our research. While the following findings may not specifically relate to the issue of data collection processes, they do provide qualitative information as important context for understanding current data on the implementation of the Directive and may provide useful context for the development of approaches in the future which can lead to better quality data on the Directive in a fashion that eliminates gaps of the nature which currently exist.

What influences a patient's choice/decision to travel for care?

Captured below are some of the opinions that were shared by respondents in the course of interviews or workshops. These are not direct quotations, but provide snapshots of some of the issues which may underlie patient mobility and the problems of collecting robust data on patient mobility.

- In Luxembourg a decision to travel for care is often based on family links, reference was made to people of Portuguese origin who prefer to seek treatment in Portugal, possibly for language or family reasons. As roughly 16% [75]of the Luxembourg population is Portuguese such cases are not infrequent.
- Healthcare professionals are seen as significant influencers of patients' decisions to travel for care. This may arise because many healthcare professionals in Luxembourg have trained in other EU countries and may refer to former colleagues.
- In France the complexity of the prior authorisation procedure is seen as a significant financial and psychological burden to patients wishing to access care abroad. A recent initiative of the TRISAN project to develop a comprehensive on-line information tool, the ' Guide de Mobilite', is at present focussed on the Upper Rhine region, but may provide a useful model for adaptation and replication in other regions, and for scaling up in respect of other border regions involving the Member States which the TRISAN initiative currently covers.
- Prior authorisation is a problem for both reimbursement routes
- Not enough patient reimbursement is a problem in the Directive route, often leaving patients out of pocket.
- National reimbursement rate disparities are this is beneficial for some patients e.g., if travelling from LUX to France but when travelling to a higher cost area this becomes an obstacle and may be a disincentive.
- It is difficult for French patients to distinguish between the Regulations and the Directive and to understand which mechanism would be best for them to use

[75] https://statistiques.public.lu/en/news/population/population/2018/06/20180608/index.html

- It takes 2 years on average for an insurance scheme to become known and used- this is an information issue- patients will simply not travel where they don't have info.

How do citizens in the region get their information on cross-border healthcare opportunities?

- There is a desire to simplify things for patients and make things clearer for professionals and authorities.
- The Guide de Mobilite developed for Upper Rhine is a significant step forward in providing extensive, comprehensive, and scenario-based information for patients- this should be adopted elsewhere and is relevant for all mobility on the German/French border.
- The Euregios as local structures could have a role in promoting mobility information.

What role do health insurance providers play in facilitating cross-border patient mobility in the region?

Health insurers in this region play an important role as facilitators of patient mobility and also as holders of data which can generate evidence to inform a more coordinated approach to cross-border care.

Insurers in the Grande Region generally encourage case by case approach to patient getting very clear information on their specific options.

In the case of France, as the national health insurer, some indication was provided as to the kind of statistical data gathered –At present, the balance of activity between the Regulation and the Directive cannot be disaggregated or broken down but this may be something reviewed in the future.

The French national insurer has cooperated with initiatives such as the TRISAN study and is providing data for this to support exploration by TRISAN of the potential for a new bilateral agreement for North Rhein.

Why are there gaps in data on cross-border patient mobility?

The level of data collected and its nature is determined by a variety of different considerations and purposes underlying data collection. While insurers and others have collected data around patient mobility, there is currently no common framework for data collection and no common template for the region. This is something that a proposed overarching data observatory model could address.

What are the future possibilities for cross-border patient mobility in the region/what are the dependent factors for this?

It is beneficial to have clusters of agents in border regions, including insurers, who can work together in innovation processes which benefit all the stakeholders in terms

of institutional priorities but also benefit citizens and patients. Regional territorial alliances for health have the potential to offer Member States new ways of working in respect of access to healthcare and the health of their border populations- significant sections of national populations live in border regions yet the cross-border healthcare spend is only 1% of national budgets. Health inequalities remain in these populations.

If treated in a cross-border context which embraces the principle of territorial complementarity and cross-border patient catchments, the issue of providing patients with choice and opportunity is not diametrically opposed to the issue of providing HCPs in border regions with professional opportunities and ensuring catchments are maintained for safe provision of particular healthcare specialties. Without a cross-border approach, hospitals will continue to be concerned about 'losing' patients to the other side of the border. The regulation and Directive can become creative tools for Member States to address ongoing issues with access to health services and the health outcomes of their domestic populations.

In Grand Est, urgent patient transfer was assessed. It became apparent that there was no pre-agreed process for requesting cooperation from neighbouring countries on urgent patient transfer, and the Agence Regional de Santé (regional arm of the national French public health authority) did not have the authority to make or authorize the receipt of cross-border patient transfers. This situation was partially addressed by adaptation of a bilateral hospitals' agreement in Eastern Lorraine and Saarland/Saarbrucken. There is an opportunity for French healthcare authorities to explore what the benefits may be of Eastward cooperation for patients in that area of France.

There have been some positive effects arising from the crisis of patient transfers experienced in Saarland/Rhineland-Palatinate and this includes regional presidents in the cross-border area entering into a pact of mutual support and assistance which was launched in summer 2020. While a *Pacte d'Assistance* is not considered binding under French law and is essentially a political agreement, there is further opportunity for the French national authorities to explore their potential role -via Agences Regionales de Santé- and the benefits of a global collaborative approach along the French border for French patients.

Local self-government can work to open new pathways of cooperation at a political level and improve connections between central and decentralized authorities. There exists a high degree of analysis at technical level as to what is required in relation to patient mobility and cross-border healthcare cooperation but this needs to be complemented and augmented with decision-making level endorsement and authority of state agencies. There should be exploration of information-sharing between ARS Grand Est and regional/local self-government around population health- this would build on the positive impact that sharing of COVID-19 information between authorities has had.

It is understood that for successful global cooperation on patient mobility in the context of population-based healthcare for citizens living in border areas, the involvement of the Member State may be crucial- and this may also provide the Member State with an opportunity and pathway to develop innovative solutions for

its patient-citizens- either through innovations in local service delivery and/or through collaborative working and mutual support with authorities along its borders. In any case, there is an opportunity for deepening peer-to-peer working relationships between local self-government cross-border structures with the political support to address border issues and specific agencies within the territory of a cross-border region such as health authorities. This will be the key to the future and can benefit all; it is also consistent with the cohesion concept of a Europe closer to citizens and with the acknowledgement of the role of border regions in European cohesion for the benefit of citizens.

There is a need to build on the strong legacy of healthcare cooperation and the notable asset of regional civic support (and significant skills capital to drive a structural approach to cross-border collaboration as an integral feature of public services) in the Grand Est region. Institutional cooperation needs to balance the development and delivery of core projects and both complement each other as essential components of successful cooperation- this is the case as regards cross-border health and patient mobility issues. A good practice example, relevant for the Grande Region, is the work of Eurodistrict PAMINA in this regard.[76]

The next stage of healthcare cooperation- and facilitation of cross-border patient mobility in this context and that of the rights of patients as EU Citizens- is to collaborate on innovation. There have been consistent longitudinal efforts to focus on cross-border healthcare and health, but this has been in the absence of authorities embracing a WHO model of population health and an integrated care philosophy. There may now be an opportunity, in the context of what the COVID-19 pandemic has revealed, for innovation which brings together the structural, the institutional, and the individual within a territorial, place-based approach for border regions- which focuses on an integration of healthcare policies with the patient-citizen at the centre. While there is communication between stakeholders and regular project-focused collaboration, this has stopped short of integrated systems being developed on a cross-border basis and perhaps now is the time to pursue such solutions for the future- especially in view of the learning from the COVID-19 pandemic and the need to create resilience and recovery.

There should be further local mapping of the conditions put in place by individual healthcare insurers for reimbursement- this needs mapping locally and needs to inform the shared development of integrated approaches at the level of specific cross-border communities- such as the model being pursued by Ems Dollart Region[77] which also informed this Dutch-German Euroregion's contribution to the *b-solutions* project relating to obstacles to cross-border patient mobility and reimbursement issues across local borders.

While there has been extensive work done by the working groups of the Grande Region, further work is needed to ensure a change is delivered and this necessitates participation and involvement of the right personnel at the right level of authority within healthcare authorities in some countries, to match the level of participation by

[76] Eurodistrikt PAMINA, Europäischer Verbund für Territoriale Zusammenarbeit (eurodistrict-pamina.eu)

[77] Ems Dollart Region : https://edr.eu/?lang=de

others.

Delivering successful structural and institutional cooperation with the patient at the centre of the process necessitates having appropriate involvement from healthcare authorities at a sufficient level of authority and seniority in order to be able to deliver- much healthcare cooperation to date may largely have featured involvement of personnel on an experimental basis who may often not be in a position to influence a corporate shift within their own organisations. Organisations embedding learning from healthcare cooperation into their normal business is a step beyond the experimental.

For improved patient access and healthcare cooperation to benefit all in Grand Est, an intergovernmental approach is needed. Cooperation exists in several bilateral arrangements which national authorities work within and are happy to support- but these are a confluence of two-party agreements e.g., ZOAST. Things are more complicated on the France/Germany border due to differences arising from a centralized state structure in France and a federalized state structure in Germany. This can result in different personnel being involved depending on the specific geographical part of the border, and a lack of a generic or more widely applicable approach where the two countries are involved. The Aachen Treaty[78], signed by France and Germany in January 2020, and which commits to deepening cooperation in business, society, politics, and technology, could potentially form a driver for future collaboration on some of these specific issues.

There has been significant work done in specific subregions to address and progress cross-border patient mobility issues- a good example of this is the TRISAN Guide de Mobilité. Tools developed specifically in one part of the France/Germany border region are relevant for all cross-border patient mobility between the countries and perhaps some work can be done at institutional/public authorities' level to ensure that this information can be shared and built upon for all patients who would benefit from it.

In the wider Grande Region of which Grand Est is part, an example of good practice is being produced in 2021 by the Working Group on Cross-border Health, chaired by Mme. Agnes Chapelle, which will provide a legal template for framework agreements between all players.

Regions have a role in bringing Member States into solutions which address care issues on borders. Regions operating strategically can offer solutions and act as partners to Member State administrations in determining the best approaches to meeting the needs of their citizens who reside in border areas. High-level agreements such as the Aachen Treaty, and the proposed ECBM[79] - a European instrument- could potentially have roles to play in this in the future for this region.

[78] https://www.diplomatie.gouv.fr/en/country-files/germany/france-and-germany/franco-german-treaty-of-aachen/

[79] ECBM: https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM%3A2018%3A373%3AFIN

What would better data do and who is interested?

Responses to this question included the following key points:

Grande Region has a large number of cross-border workers and better data would inform a more coordinated approach to planned healthcare- this especially important in the context of post-COVID-19 health system recovery issues.

Grande Region has an integrated regional data dashboard- GIS system which informs economic and social /labour market integration evidence and could also accommodate and host exported healthcare statistical data. This could form the basis for integrated healthcare and patient mobility data for the cross-border Grande Region and become a significant game-changer in terms of the level of institutional innovation and authoritative cooperation that could be based on this validated evidence base.

Better data could facilitate more structured working on creating access and services for specific patient groups, within the context of the Territory for Health Agreement (1995) and particularly would facilitate a cross-border territorial approach based on complementarity of all healthcare offerings/assets/centres of excellence in the region. Most conventions which exist in the region don't require PA for reimbursement and this is a strength which means the burden of organization is not on the patient.

Additional key points made relating to this question were:

- We need conventions that allow patients to cross the border without hindrances.
- We need to fight back against red tape- there are 20,000 patients going between France and Belgium per annum.
- We need to do more on the proximity concept- the patient's closest point of care may be across the border and an analysis of data- if collected properly and providing some perspective on geographical population demands- will assist with creating access.

Better data, in this sense, can reduce the risks to patients and improve outcomes, supporting the creation of a truly cross-border regional strategic framework for health policy and interventions.

What impact has COVID-19 had on cross-border patient mobility in the region?

The survey indicated that the prevailing perception is that fewer patients have crossed the border for planned care in the case study region, due to border and travel restrictions. A number of survey respondents also indicated that the COVID-19 crisis had led to new forms of healthcare cooperation in the region. Waiting lists for planned care have increased as a result of the COVID-19 crisis and the diversion of resources away from planned care operations and into responding to the unscheduled care crisis of COVID-19.

Focus groups and interviews raised the following additional observations by

respondents in the study:

- Learning that cooperation can be accelerated in times of crisis, and the degree of preparedness is revealed either positively or negatively. Where relationships exist on borders solutions can be found. More patients used ZOASTs during the pandemic- more than 300. Cross-border workers not travelling may account for a 25% reduction in mobility figures.

- Paradoxically, COVID-19 placed health at the top of Member States and the EU priorities list—all collaboration had a sharp and exclusive focus on COVID-19 but perhaps some of the learning and the experience of possibility could be applied to other kinds of future population health needs in border areas. Patient transfers were not common. Only focusing on COVID-19 related healthcare cooperation will lead to over-specialisation. The matter of non-COVID-19 healthcare should come into focus and the innovation achieved during this period of disruption could deliver positive outcomes if sustained.

- There was a strong political will driving the governance and provision of authorisations for public authorities to cooperate on health issues in the context of COVID-19, and rapidly improved communications happened around patient mobility in the context of the pandemic. This perhaps augurs well for future practice.

- While there was an impact on cross-border patient mobility data for 2020 the decrease was only 25% of reimbursement claims in the case of France.

- COVID-19 revealed issues with lack of interoperability of patient health records- for example, a German working in France is not registered with the French health system.

- Large numbers of urgent patient transfers happened in the Grande Region

- On 11th December 2020, there was a health ministers' joint press conference which focused on drawing lessons and building cooperation within the Benelux Structures.

- According to the French national insurer, during the first lockdown, even when travel restrictions and cross-border mobility were very strict, there was no massive fall in CBPM. They were surprised at this- for example, regional cross-border Tourism figures had decreased by 70% in 2020, so they had expected a reduction of around 50% in claims but 2020 saw only a reduction of 20% in claims- this would suggest that some stability in cross-border patient mobility was retained in the Grand Est Region. People close to the border continued to receive their healthcare in other countries. During the second and third lockdowns in later 2020 and into 2021, people still travelled 30-50 kilometres across the border. It is possible that frontier workers- especially those in the health, care, and essential services sectors, may have temporarily domiciled in neighbouring countries and accessed care there while seeking reimbursement. There was a rise in the level of reimbursement claims to cover the cost of COVID-19 testing.

- When the COVID-19 crisis came it was obvious after a short time that our basis for working in healthcare was not fit to respond to the crisis, especially on borders.

Further Observations on the Directive and patient mobility:

The level of existing knowledge and institutional capacity for navigating cross-border patient mobility issues at practical and policy levels in the Grande Region led to high-quality input to research engagements, both in the context of focus groups and interviews. Participants were well-informed about the scope and potential of the Directive, and these comments have been summarised here for the purposes of completeness:

Travelling for care is only one dimension of what the Directive can facilitate. There is the matter of health tourism for care such as elective dentistry, and a separate issue is the more territorially relevant issue of reflecting on population health needs in border areas and on approaches and solutions which will deliver better population health outcomes. This is for the Member State and regional actors to determine and decide what to do. There is an opportunity to move the needle in terms of access to care, and this requires moving beyond a 'bare minimum' approach to implementation of the Directive- to date in the Grand Est and Grande Region it is used very seldom and largely for the reimbursement of care in private hospitals only.

The Directive while facilitative in concept, can in practice hamper rather than enable patient mobility. The provisions within the Directive mean that Member States could be the single determinant in what kind of patient mobility occurs under the Directive.

There is a potential conflict of interest in the insurer- be that a national insurer or other type of insurer- being the only source of information to patients to allow patients to make decisions. Information to patients should be independent of the insurer. There are ethical issues relating to the need for independent information that need to be looked at in this regard from a citizens' point of view.

3B.6 Analysis

It is clear that a wide variety of data are collected at the national levels and by various regional and local cross-border collaboratives for the purposes of their activities and for the purpose of generating evidence specific to individual collaborations and/or reporting on cross-border patient mobility. These initiatives have developed over time and at different paces, in response to different stimuli and considerations.

There is, however, the opportunity for this significant capacity, both in Grand Est and in the Grande Region as a whole, to develop a more overarching and comprehensive territorial geospatial approach to collecting and using data on patient mobility. Such data, as a subset of overall population health data and healthcare operations data, could be used to enable mobility reimbursement mechanisms to be exercised to their full potential. The data also be used to inform actions at the level of Member States and at the level of cross-border regions which have populations with particular health and cross-border mobility needs and opportunities- this includes the Directive.

Good data, available on a consistent basis and collected according to an agreed template which can inform subsidiary actions at the level of a cross-border region, will improve the extent to which reimbursement mechanisms are used within the existing terms for those mechanisms. Although it is not the purpose of the Directive to increase cross-border patient mobility, the Directive as implemented can still have greater positive impact on in-country provision planning, and on the health status of border populations, if better data on its use were available. It is recognised that data on health and patient mobility will be of limited value if it is only collected for the purpose of reporting on the Directive, but the quality of data on the Directive may be raised if it is placed in an applied territorial context of overall healthcare access planning and facilitation of mobility.

The benefits of regions and national administrations working together on data collection and use are mutual and should be understood as such. Next steps for the Grand Est Region should focus on consolidation and systematising the data that can be generated by a proliferation of existing cross-border health cooperation. Such an approach will create a more integrated approach at the level of the cross-border region to a multiplicity of drivers which now face both border regions and Member States, particularly the territorial cooperation agenda, and the core principles of EU Cohesion policy which include digitalisation (including Smart Regions), a Europe closer to citizens, and balanced growth.

3B.7 Case-Specific Recommendations

Specific recommendations relating to this case study are as follows:

- Consideration should be given by all stakeholders involved in cross-border healthcare in the Grand Est region to agreeing and codesigning a common framework for data capture, data collection, and pathways for the application of knowledge which such data can generate. The commitment by the Grand Est Region to a consolidated observatory model which uses a geospatial approach to health and patient mobility data for the regional population should be considered for its capacity to create better data at the level of the cross-border territory, which can inform future service planning, healthcare investment (both clinical workforce and capital investment), both at the level of the cross-border territory and within the constituent Member States.

- Consideration should be given by those driving a Grand Est observatory initiative as to how this can work for the wider benefit of the Grande Region, as a macro-region which, although not specifically the focus of patient mobility figures in this study, nevertheless provides an established community of interest in cross-border healthcare cooperation and creation of pathways for citizens to access care within the cross-border territory, including care that involves crossing borders.

- Healthcare, population health and patient mobility data generated in any ongoing collaboration should be considered as valuable in its own right but also integrated into wider geospatial data repositories or dashboards. Health

and patient mobility data are significant indicators of wider economic health and of social need and therefore have information value beyond their immediate application in the area of healthcare service planning or patient mobility pathways.

There is significant value in the availability of patient information on cross-border mobility which is pro-actively communicated through channels which are not confined to those information channels operated by healthcare insurers. Regional authorities, as custodians of civic and citizens' interests, have a role to play. The TRISAN *Guide de Mobilité*[80] for Upper Rhine will offer information that is relevant for other areas of the Grande Region and consideration should be given to how the investment in this Guide can have additional value-added effects for all patients in the Grande Region for whom the information may be relevant in deciding whether to cross the border for care.

The TRISAN patient mobility guide has been identified as a model of best practice by this study. It is designed to provide an online patient information tool which has been developed through an evidence-based approach to provide personalised information around patient mobility information and entitlements, which can be used by a patient living in Upper Rhein to present to their insurer in the context of arranging to access healthcare across the border. For further information on the Guide, visit: Leitfaden für die Patientenmobilität am Oberrhein - Trisan - Trinationales Kompetenzzentrum für Ihre Gesundheitsprojekte

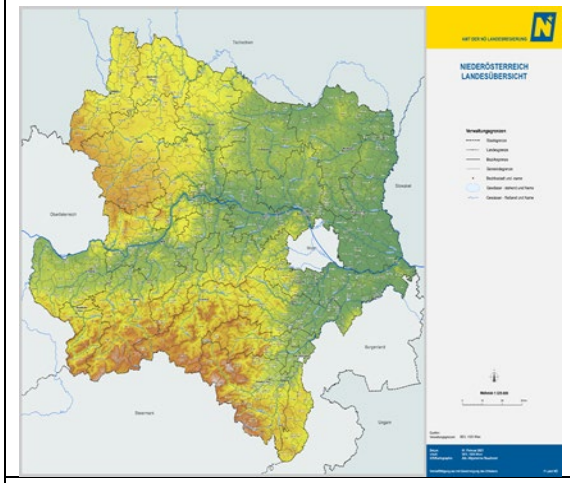
[80] Leitfaden für die Patientenmobilität am Oberrhein - Trisan - Trinationales Kompetenzzentrum für Ihre Gesundheitsprojekte

3C Case Study 3 - Lower Austria/South Bohemia/Slovakia

3C Table of Contents for Lower Austria/South Bohemia/Slovakia

Lower Austria/South Bohemia/Slovakia	Summary of Findings - Key aspects of cross-border patient mobility **Key players:** Local GPs, local hospitals and care providers, Healthacross **Sources of information:** National Contact Points, Healthacross representatives, Lower Austria Health and Social Fund representatives, key clinicians, responses to questionnaire, 2020 Annual Report on Directive, 2020 Annual Report on Regulations (both citing 2019 data)
***Who** are the key players?* • ***Who** uses care?* • ***Who** informs care?*	•Local clinicians and public sector actors in numerous cross-border care projects spanning more than ten years are the core drivers of cross-border care between key cities in the region. • Cost of care under the Directive remains a big barrier for patients from Czechia and Slovakia, Healthacross and other projects have helped to address this barrier. It was noted that for those able to bear the cost of care in a neighbouring country the system worked well and was well understood. •Hospitals, GPs and Healthacross were reported to actively promote the possibility of cross-border care, with targeted information to certain patient groups and also at key times of the year – e.g., summer holiday period.
***What** cross-border care accessed ?* • ***What** types of care are accessed?* • ***What** influences patient mobility?*	• All types of care are accessed, but focal points exit around maternal and neonatal care, particularly in Gmünd and also between Hainburg (Austria) and the children's university hospital in Bratislava (Slovakia). Pregnancy and Birth was the single biggest care category in the data provided by the insurers, but the biggest patient group was from the United Arab Emirates. • A key influencer of cross-border care is local proximity to care, both specialist and routine. • The historical context of towns and cities which have in the past century 'moved' as new land borders have been drawn, creating mobility among the population based on a shared history.
How** is cross-care reimbursed?* • ***Regulation • ***Directive*** • ***Other***	The data provided by the NCPs on patient mobility in 2019 indicate that Slovakia is a relatively high user of the Directive, with roughly 10,000 patients travelling of whom 5,000 travelled to Czechia for care not requiring a Prior Authorisation (PA), Czechia however reported only in total 916 reimbursements not requiring PA and Austria only7 in total. not requiring PA Concerning the Regulations, the Czechia and Slovakia are relatively small users, but Austria reported issuing 4,489 PDS2 for Germany, accounting for 13% of all PDS2s issues in 2019. **Regulations** - Austria and Czechia report very limited use of the Regulation, with Austria reporting 6 PDS2s for care in Czechia and non for care in Slovakia; Czechia issued 62 PDS2s or care in Slovakia and Slovakia issued 855 PDS2s for care in Czechia. **Directive – Slovakia** reimbursed a total of 5414 cases of care under the Directive in Czechia in 2019 (of which 5109 without PA); **Czechia** reported 197 cases of reimbursement without PA in Austria and 130 in Slovakia; Czechia does not use a PA system. Austria reported no use of the Directive for care in Czechia or Slovakia and only 13 reimbursements in total under the Directive in 2019. Austrian insurers have collected data on all care provided in 2020 in the 25 hospitals of lower Austria to patients not holding Austrian insurance. These data show that 19,632 patients not insured in Austria received care in a hospital in Lower Austria. Of

	these 636 were resident in Czechia (173 also had Czech citizenship) and 555 resident in Slovakia (229 also had Slovakian citizenship). It would seem therefore that the number accessing cross-border care as understood in the EU legislation is small. These numbers include patients who benefitted from the Healthacross project where any difference in payment for care that might have been payable by the patient was absorbed by the project. In total, approximately 7,000 patients have benefited from Healthacross in the past 10 years.

Summary of Findings- Qualitative Conditions for Cross-border Patient Mobility	Key Actors	The Future	
Lower Austria/South Bohemia (Czechia)/Slovakia 	**Health Across** **NOEGUS** **Gmund Hospital community** **World Health Organisation** **A WHO Region of good practice in healthcare cooperation**	**Health and patient mobility data collaborative involving regional actors, healthcare providers, health insurers, the NCPs, and other relevant stakeholders** **Better data means better possibilities** **Explore innovative patient financing mechanisms**	**State-level agreements for more shared approaches to care?** **NCPs and Health Across- compare and explore existing data** **Cross-border approaches to planned care post-COVID-19** **Advance cooperation in Thoracic Cardio-Pulmonary surgery, maternity, neonatal and mental health services**
Proximity matters in patient-centred care- for many the nearest point of care is across the border	**Clinical commitment – duty of care to a cross-border patient population**	**Consistency of approach and legal templates for bilateral cooperation**	**Maintain WHO involvement with future collaborations**
Provision is made for the language needs of patients and services at Gmund are promoted with patients	**Directive places burden of cost on the patient**	**Independent, well-coordinated information for citizens in their own language**	**Moving from INTERREG funded to mainstream resourcing**

3C Case Study 3 - Lower Austria/South Bohemia/Slovakia (AT/CZ/SK)

3C.1 Context for Cross-border Patient Mobility in the Region

The Lower Austria region, bordering with Czechia and Slovakia, features significant capacity built up over a number of years, for cross-border cooperation in delivery of healthcare to a cross-border functional area and patient catchment. A key location for delivery of services to patients from neighbouring jurisdictions is Gmünd hospital. Gmünd is a city with a cross-border hinterland and in this context, delivery of care-officially understood as care 'abroad' is very much a matter of 'local' care.

The key organisation responsible for driving and providing leadership for cross-border cooperation in healthcare in Lower Austria is Health Across, working in partnership with NÖGUS amongst other insurers, to deliver a range of interventions for the population catchment of the cross-border territory in question.

Healthacross operates on a strong value base of equality and removal of barriers to access, and the organisation states its core purpose as combining 'regional and supra-regional national interests in the health sector in the form of international networking, cooperation and exchange of information, in particular through the initiation and implementation of innovative, cross-border and international projects in the health care sector in the sense of the Lower Austrian state strategy.[81]

Healthacross represents Austria in a number of international networks focusing on cooperation in healthcare and transboundary cooperation for health in populations. These are:

- WHO Regions for Health Network (WHO RHN)
- DART (Declining, Ageing and Regional Transformation)
- HoNCAB
- EUREGHA
- eu Prevent

The World Health Organisation (Europe)[82] has recognised the work undertaken by Healthacross and partners as an example of the kind of collaboration which will be increasingly required in the field of healthcare at borders. This issue has been highlighted in the European experience further by the experiences at borders during the COVID-19 Pandemic and in the role played by border regional organisations in responding to the crisis at national borders and for cross-border populations living in cross-border functional areas. Identifying not only the growing relevance of cross-border cooperation for service standards and equality of access issues in health, the WHO highlights the benefits to Member State administrations and health systems of cross-border cooperation in health:

'(Cross-border Cooperation) can also help in optimizing costs due to the shared use of resources and a better return on resource investment. Moreover, the diffusion, dissemination and implementation of innovative and effective public health

[81] About us (Healthacross.at)

[82] WHO/Europe | Lower Austria as an example of cross-border cooperation in health care

interventions are ongoing challenges for the public health workforce and especially the specialist involved in project and policy development'.

In this context the WHO has identified Lower Austria as a region of good practice in healthcare cooperation through the investment of resources over time in shared approaches to service delivery and population access to health services. The WHO also notes that Healthacross works closely with the Health and Social Fund of Lower Austria (NÖGUS) and through this connection has participated in significant levels of European cooperation focused on both delivery and policy associated with regional health and cooperation.

Healthacross has coordinated the delivery of a range of significant cross-border cooperation projects, including those funded by the EU INTERREG programme, in the area of health service provision and access to health services. This body of work represents the environment and context for patient mobility in the Lower Austria, Bohemia and Slovakia region which has been the focus of this AEBR/DG SANTE case study. The following overview of these initiatives is drawn from Healthacross public information on the organisation's website and is important to include in this case study as these projects provided the context for the contributions of research respondents. The initiatives detailed were also heavily referenced during discussions which took place during the research phase.

Healthacross, in its own words, has delivered the following initiatives as distinct work packages and pilot activities in the years preceding this case study:

"Healthacross" aimed to provide optimum usability of health services and equal access to health care by all people living in the border region of Lower Austria and South Bohemia (Czechia), through close cooperation among health service providers in the project region. Results of this two-year project include the publication of guidelines for action on cross-border health care provision, and an analysis of the forms of cooperation between Lower Austria and South Bohemia that were implemented, including emergency care (i.e., the use of existing facilities versus the establishment of a new cross-border health centre).

Key initiatives delivered by Healthacross to date:

Healthacross in practice:

The follow-up project, "Health across in practice", enabled Czech patients from the border region of Lower Austria and South Bohemia to have uncomplicated access to medical treatment at the Landesklinikum Gmünd in Austria. In the pilot period from 25 February 2013 to 30 June 2013, around 100 Czech patients received outpatient treatment in Austria. The pilot project was institutionalized and more than 2800 Czech patients have received outpatient treatment at Landesklinikum Gmünd.

Health without borders:

Future cross-border cooperation in health care provision was established between Lower Austria and the Czech regions of South Moravia and Vysocina. The aim of the project was to elaborate strategic opportunities for cross-border cooperation between hospitals and to organize a cross-border contract for emergency services. The project tried to overcome language barriers by providing language courses in health care facilities and by publishing a phrasebook titled "Czech language for health

care services".

The follow-up to Healthacross in practice:

The main focus of the new project with South Bohemia is to ensure permanent outpatient treatment of Czech patients in the hospital in Gmünd (Lower Austria), to expand the project by providing inpatient care, and to search for opportunities for a long-term cooperation in terms of a cross-border health care centre in the border region of Gmünd/Ceske Velenice (Czechia).

Follow-up project 'Together Unlimited Healthy'

This project will focus on cross-border hospital cooperation in radiotherapy and gynaecology (endometriosis) in Lower Austria, South Moravia, and South Bohemia. It will also develop software to link emergency coordination centres for cross-border scheduling of emergency vehicles.

'Bridges for Birth'

This project aims to build up cross-border cooperation for neonatology care between the hospital of Hainburg (Austria) and the children's university hospital in Bratislava (Slovakia). The main objective is to transfer newborns who need neonatology care from Hainburg to Bratislava because the hospital in Bratislava is only 15 km away; the nearest neonatology care unit in Lower Austria is more than 85 km away.

In participating in the AEBR/DG SANTE research, Healthacross both responded and facilitated networks of respondents for the research, drawing together stakeholders from within its networks from the insurance, clinician, healthcare management and cross-border cooperation programme management fields. Both qualitative and quantitative data were supplied for the purposes of the research.

Additional responses to the research enquiry in this case study came from healthcare (national) insurers in Czechia and Slovakia. The umbrella organisation for health insurers in Austria also actively participated in the research.

Additional perspectives on the context for cross-border patient mobility in the case study region can be summarised as follows:

A clinician perspective highlighted a clear commitment to serving a cross-border population through Gmünd hospital and an iterated duty of care. The hospital offers a range of diagnostics and interventional services including in the area of Cardiology, for which there is an established level of need in the patient catchment (itself a cross-border patient catchment).

Gmünd hospital has also been proactive via Healthacross in providing information to the Czech population within its patient catchment, through events and ongoing provision of information on a pro-active basis. While there is a degree of bilingualism in the population and in the clinician population, the hospital nevertheless recognises the relevance of language accessibility as a care quality issue and to address what would otherwise be a potential barrier, the hospital has interpreters in place and staff are often bilingual. It was also highlighted during the research that Healthacross and partners established links with Meuse Rhine- another of the AEBR/DG SANTE case study areas- specifically around sharing best practice on provision of information

to patients around entitlements and service access.

Clinicians also operate on the basis of patient choice in cases where onward referral for speciality or additional secondary care is required by a patient. Gmünd hospital offers the choice of a referral to either an Austrian or Czech specialist and the patient makes the decision based on their preference.

Gmünd sees a considerable patient flow in the area of Obstetrics and Gynaecology Services, particularly from Slovakia. It is estimated that approximately 40% of patients seeking these services are from Slovakia. Gmünd Obstetrics services are described as 'primary' level with 25 beds and 500-570 live births a year. The Obstetrics and maternity service offered at Gmünd, within the framework of the 'Bridges for Birth' initiative is a multidisciplinary, personalised care offering which offers maternal choice and places the women at the centre of their own birth planning and decision making. It is understood that women in the region appreciate the concept of proximity to appropriate maternity services and that this is a factor in patient choice to travel across the border to Gmünd. Average length of stay for maternity patients is between 2 and 4 days.

Respondents specifically emphasised the role which the EU INTERREG programme has played over a number of programming cycles, as being critical. The programme provided the resources to establish the requisite levels of cooperation in healthcare in the region, together with the required levels of clarity and accountability in order for learning and mainstreaming of pilot activity to be achieved. Respondents remarked that without the INTERREG programme the level of health-related cooperation in the case study region would not be where it is in the present day.

Stakeholders within the Healthacross initiative also emphasised that cross-border patient mobility is best facilitated with the patient as a core partner, that communication and awareness are key for success, and that there is an ongoing need for cross-border champions within every domain of healthcare cooperation at borders- these are factors in the success of cooperation in this region to date.

In this context, the issue of better data on patient mobility was recognised as a distinctive issue which would involve additional stakeholders or different departments of Healthacross partner organisations.

3C.2 Member State Health Systems

This section provides information on specific provision by the health systems relevant for the case study. The European Commission's Health at A Glance report[83] is produced annually in cooperation with the OECD and the European Health Observatory for Health Systems. It provides high-quality and in-depth information on Member State population health status, risk factors, health system performance reporting, and analyses developments in overall healthcare system resourcing and administration for each Member State. In understanding the key features of the various health systems in the Member States relevant to the case study areas, the

[83] Country Health Profiles | Public Health (europa.eu)

French Government's *Cleiss*[84] website also provides information fiches for countries globally which focus on information on types of healthcare provision in-country.

The Health system features for the Member States relevant to our case studies are summarised as follows:

The Austrian Health System:

Health care expertise is shared between the federal and regional levels, with the central level delegating many responsibilities to local agencies. The Austrian system is characterized by a mixed funding model, in which the state and social health insurance contribute almost equally.

The main players in the Austrian health system at the national level are the Federal Ministry of Health and the Federal Ministry of Labour, Social Affairs and Consumer Protection, the states (regions), statutory social security agencies and the Central Association of Austrian Social Security Agencies as a confederation, interest groups (social partners): employers' and workers' associations and professional interest groups) and the various health care providers.

In Austria, health care is based on a social insurance system that guarantees all inhabitants equitable access to high-quality health services, regardless of age, gender, origin, social status, or income. All policyholders are entitled to a large number of benefits:

- primary health care provided by doctors contracted by the Austrian Social Health Insurance Funds,
- emergency or specialized care, outpatient or inpatient care, including maternity care,
- psychotherapy care,
- health check-ups or laboratory tests,
- rehabilitation, occupational therapy, speech therapy or physiotherapy,
- Dental
- dispensing prescription drugs,
- dispensing devices or medical devices,
- ambulance transport,
- home care,
- access to health prevention and promotion services, including vaccinations or screenings,
- rehabilitation and long-term care services,
- care for people with disabilities.

The Czech Health System:

Czechia has a legal universal health insurance system based on compulsory affiliation with a health insurance fund. Funds are public and self-governing organizations that act as payers and purchasers of care. Eligible people residing in

[84] Centre des liaisons européennes et internationales de sécurité sociale

the country can freely choose their health insurance fund and health care providers. Health insurance funds must accept all applicants, as risk selection is not permitted.

Medical services are provided by health centres, hospitals and other health professionals contracted with Czech health insurance funds. The insured chooses one of the seven of those responsible for administering social insurance. The main one is the general health insurance fund (*Všeobecná zdravotní pojišťovna*). Health insurance funds also collect health care contributions.

With regard to the relationship between the Czech health insurance system and the various health providers, framework negotiations take place regularly between representatives of health care providers, health insurance funds, hospital associations, scientific organisations, and patient associations. Framework contracts are the result of these negotiations.

On the basis of these framework contracts, health insurance companies enter into their own contracts with certain health providers. The terms set out in these individual contracts may be partly different. A health care provider can enter into a contract with several or even all health insurance funds. Only a very small percentage of health care providers do not have a contract with a health insurance company.

Benefits covered, in full or in part, by the Czech health insurance scheme include:

- Preventive care
- Curative care
- Emergency care
- Long-term care
- outpatient and hospital care, including rehabilitation and chronic care, psychotherapy;
- care and dentures;
- medicines and medical devices (prostheses, acoustics, glasses).

In the case of dental treatment, only basic equipment and basic treatment are covered.

The Slovakian Health System:

The health care system in Slovakia is based on universal coverage, compulsory health insurance, a basic benefits package, and a competitive insurance model with selective contracts for health care providers and flexible pricing of health services. Health care, with one exception, is provided free of charge to the insured and care is paid directly to health care providers by insurance companies (paying third-party system).

Health policy is the result of interaction between the Ministry of Health (legislator), insurance companies (care purchasers), health care providers, professional organizations, and the health care supervisory authority. Patient organizations have little influence on the formulation of health policies. The state has the largest hospitals and the largest health insurance company.

Public health operations are traditionally organized separately from health care services and focus on surveillance of communicable diseases. The Ministry of Health oversees the public health network in Slovakia, which is funded exclusively by the state budget.

Insurance covers all or part of the following risks:

- outpatient care provided by contracted or unsigned physicians,
- hospital care, emergency care, obstetric care,
- medicines and medical devices,
- diagnostic and therapeutic services,
- urgent dental care,
- transporting the sick person by ambulance or air rescue services, preventive medicine.

3C.3 Baseline Data – Member State Data[85]

The data available in the annual reports for 2019 on patient mobility in Austria, Czechia and Slovakia indicate that both Czechia and Slovakia are quite regular users of the patient mobility mechanisms, although Slovakia has the greater number of out-going patients.

Austria had far fewer cases of mobility under both mechanisms, and although data were reported for mobility under the Directive none of the reported cases were of patients travelling to Czechia or Slovakia. Commenting on the number, Austria noted that reimbursement applications from insured persons who received cross-border health treatments that do not require prior approval are usually treated as domestic reimbursement claims and are therefore not specifically recorded.

Table 1 Austria/Czechia/Slovakia mobility under the Directive in 2019

	Issued	Received
AT & CZ	6	6
AT & SK	0	0
CZ & AT	Less than 5	Less than 5
CZ & SK	62	974
SK & AT	48	6
SK & CZ	855	974

Issued = number of PDS2 reported as issued by competent MS
Received = number reported as received by treating MS from competent MS

[85] Data report on the application of the Directive in EU countries (2019)https://ec.europa.eu/health/cross_border_care/overview_en

treatment in treating MS
NOTE: this number is not always the same, indicating reporting variability.
/ = data not provided
0 = no reported PDS2

The preponderance of movement is similar under the Regulations, where we see Slovakia issuing 855 S2 forms for care in Czechia and Czechia reports receiving 974, however other patient movements between these three countries were not highly significant.

Table 2 – Reimbursements made under the Directive in 2019 for countries sharing the Lower Austria/Bohemia/Slovakia case study region

	With PA	No PA		With PA	No PA	
AT to CZ	0	/	CZ to AT	n/a	/	SK to AT
AT to SK	0	/	CZ to SK	n/a	/	SK to CZ

/ = data not provided
0 = no reimbursements made
n/a = PA system not implemented

These data should be seen in the wider context for Austria, Czechia, and Slovakia = reflected in EU published figures on social security co-ordination based on statistical reports (2019)[86] which show that in 2019

- 171, 307 were insured in Austria but reside in another Member State
- 43,110 persons reside in Austria but were insured in another Member State
- 4,732 PD S2 forms were issued by Austria for care in another Member State
- 14,701 were insured in Slovakia but reside in another Member State
- 92,076 persons reside in Slovakia but were insured in another Member State
- 1,049 S2 forms were issued by Slovakia for care in another Member State
- 130,098 were insured in Czechia but reside in another Member State
- 86,715persons reside in Czechia but were insured in another Member State
- 168 S2 forms were issued by Czechia for care in another Member State

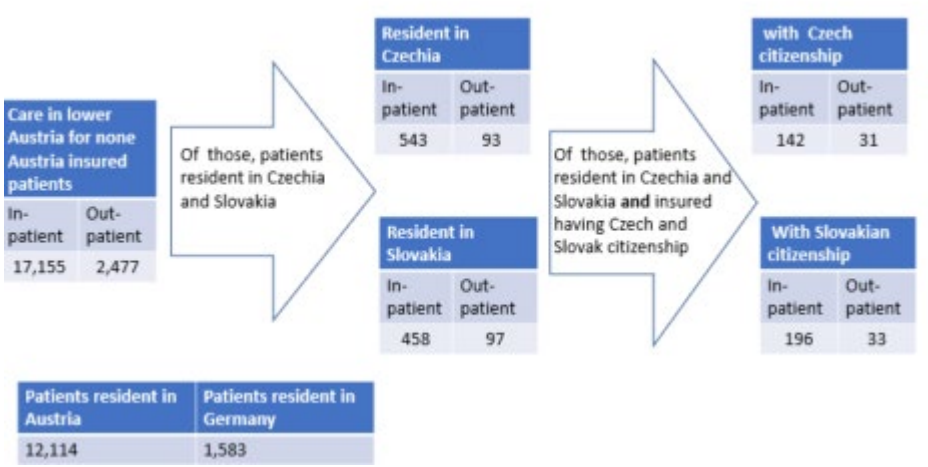
3C.4 Data Discovery Findings – What is known about patient mobility in the case study area?

In addition to the usual data gathered by the NCPs for the purposes of reporting on

[86]Austria- https://op.europa.eu/en/publication-detail/-/publication/537da209-0bf8-11ec-adb1-01aa75ed71a1; Slovakia- https://op.europa.eu/en/publication-detail/-/publication/00bd85b3-0bfb-11ec-adb1-01aa75ed71a; Czechia- https://op.europa.eu/en/publication-detail/-/publication/4c13fae0-0bfa-11ec-adb1-01aa75ed71a1

the Directive and Regulation, the Austrian insurers collect data on patients not holding Austrian health insurance who received care in one of the 25 hospitals in the Lower Austria region A deep dive into the data available for patients living in Czechia or Slovakia and receiving care in lower Austria is a good indicator of cross-border patient mobility from those countries, but it cannot be taken as a definitive picture since some of the patients may have travelled from beyond the border region and may have been treated in hospitals in parts of lower Austria which are not classified as a border region.

The complete data set shows that in 2019 the total number of cases of care provided in the 25 hospitals and care facilities in Lower Austria to patients not having Austrian insurance was 17, 155 ambulatory care cases and 2,477 inpatient cases. However, these data are for all care provided across all patients, including a total of 12, 114 cases of care provided to people resident in Austria, but not insured there. It would seem therefore that some 7,500 cases were cases of patient mobility, but a large number of those cases were patients resident in Germany (1,5833). An analysis of the data collected breaking these down into numbers that may be relevant for the Lower Austria border region with Czechia and Slovakia shows the following:



3C.5 Qualitative Research Findings

3C.5.1 Mobility and Reimbursement Issues

The data set out above demonstrate that while a significant amount of care is provided across the 25 care facilities in Lower Austria, the proportion which might be classified as cross-border care with Czechia and Slovakia is only a small proportion of that care. However, the respondent from Healthacross in Austria felt that the service offered through the Interreg projects is of major importance to those citizens living in the border region who for language, cultural and geographic reasons need to access care across the border. The respondent noted that over the past decade some 7,000 patients have benefitted from Healthacross, and explained that their needs would not be well met by the Directive or Regulation which are not suitable for people who need to access care in another country on a regular basis, or who do not fall within

the criteria that stipulate that care can be accessed on the S2 route only if it is not available, or not available in a reasonable time frame, at home.

It was noted also that there is limited need for Austrians to use the Directive because the social law (Allgemeines Sozialversicherungsgesetz) allows for patients to travel for care anywhere in the world and receive 80% reimbursement, this applies also to private care, although the reimbursement is at 80% of the social care tariff. Given that the countries which border with Lower Austria have, on average, lower care tariffs than Austria, The reimbursement rate of up to 80% of the Austrian rate as a matter of right under Austrian law limits the need for recourse to the Directive.

The respondent from Czechia noted also that Interreg is very important for filling certain gaps - e.g., there is an Austrian hospital that is much nearer for Czech patients than any in Czechia. Care in the hospital would not be allowed under the Regulations, because it is available in Czechia, but the Directive rule of reimbursement at the Czech rate would make use of the Austrian hospital prohibitive to many Czech patients. The main barrier to use of the Directive for Czech patients is the cost of care in other countries, not information or the complexity of the system. For those who are willing to bear the cost, the system seems to work well and easily. It was reported also that Czechia is very strict in its application of the Regulation, meaning that if a claim is made after care has been provided, the only route to reimbursement is the Directive, while it seems other countries are more flexible in allowing S2 to be used retrospectively.

While the Interreg initiatives are very important for those Czech patients who use them, there has been no interest in creating specific cross-border arrangements similar to those in the Meuse Rhine Region, primarily because bi-lateral agreements with foreign care providers are not allowed in Czech law. Although some Czech health insurance funds have tried to make such agreements, they have not been successful. However, it is not clear if they failed because the law did not allow it, or if the administrative burden of pursuing it was just too high.

Additional Observations

Healthacross and the other Interreg funded initiatives that have been operating in Lower Austria for over a decade all point to the value of providing focussed local responses to access to care across the local border. The numbers of people using these channels remain small when placed in the wider national context of care provided in the home country.

Nevertheless, significant efforts are being made to continue the initiatives started with Interreg funding with new national and cooperative funding schemes. In this context, quantitative data are useful and are being gathered, but it was said that they are only one element of the evidence of the value of cross-border care support that is being put forward. To a significant extent, the focus is the impact on the local communities and on the improved ease in access to care, rather than on sheer numbers of people accessing care. At national level, the insurance funds in both Austria and Czechia have no particular interest in obtaining more detailed quantitative data on regional cross-border care. In particular, for Czechia, it was felt that more detailed data collection was not of interest to the NCP nor the insurance funds.

What influences a patient's choice/decision to travel for care?

Specific observations were made as regards the decision of patients to travel cross-border to Gmünd hospital for Obstetrics/Maternity services. The hospital has a reputation for facilitating natural birth and therefore pulls from further afield than the immediate cross-border area as it has a reputation for facilitating maternal choice. The service is co-designed with doctors, and Midwifery-led.

In addition, in some parts of the Region, the national border is still perceived as new by some older citizens, who grew up in a time where the place they now live was in the other country. They therefore feel a cultural affinity with the country which is now 'abroad' and prefer to receive care there.

How do citizens in the region get their information on cross-border healthcare opportunities?

Gmünd hospital and Healthacross are proactive in providing information on cross-border healthcare opportunities to the Czech population immediately across the border from Lower Austria. This is underpinned by a stated commitment by clinicians of a duty of care to the cross-border population.

The Austrian National Contact Point's monitoring figures for information requests show that the NCP web-based information point is gaining users and that this represents progress from a point prior to adoption of the NCP Information Toolkit, suggesting that awareness amongst patients is growing in relation to cross-border care information and opportunities for care. It was noted that the Austrian experience of the NCP toolkit is that using it increases the level of confidence of personnel providing information to patients and that this has knock-on benefits for the quality of information provision and awareness outcomes for patients seeking information. It was added also that during holiday seasons information campaigns are run in ski resorts and other holiday destinations to inform visitors about their rights to care in Austria.

Focus group discussions also led to a suggestion that Healthacross and the Austrian National contact point would both welcome further contact with each other to establish additional potential for working together, particularly on the issue of patient information. This discussion expanded towards the possibility of neighbouring National Contact Points in Czechia and Slovakia participating in a collaborative conversation with Healthacross.

It was of note that during the AEBR Focus Group for this case study region, key stakeholders active at the national level and at the cross-border regional level met in person for the first time. Discussions acknowledged the benefit of being able to develop working relationships between the national and regional levels, especially when it concerns cross-border cooperation.

Drawing on the material provided for the AEBR/DG SANTE Study by the European Disability Forum on accessibility of NCP information websites, it may also be possible for further collaboration between the NCPs and regional stakeholders in the cross-border region, in relation to providing patient information which is disability accessible and takes account of the needs of people with disabilities who may wish to seek information on cross-border care opportunities.

What role do health insurance providers play in facilitating cross-border patient mobility in the region?

Focus groups and interviews produced the following key points in relation to the role of health insurance providers:

- For Austria, the Federation of Austrian Social Insurance Institutions collects the data on mobility- from all providers- for the Commission. They also get queries from patients from Czechia and Slovakia, in addition, detailed data are collected for some groups, such as the care provided in Lower Austrian hospitals.
- There are currently no insurance bilaterals in place between any of the countries in the case study area.
- Patients only use the Directive if they can't find a contract with a local provider or if the care is so specialist it is only available privately.

Why are there gaps in data on cross-border patient mobility?

Interreg projects have good data by necessity, this being linked to the stringent monitoring and evaluation requirements of ERDF funded projects. The level of performance information for Interreg-funded projects is specific and this data has been gathered for funding accountability purposes.

As regards data on cross-border patient mobility per se, in common with the other case studies within the overall AEBR/DG SANTE study, data which can yield some (and in many cases limited) information on cross-border patient mobility is generally collected for a variety of purposes and none of these includes surveillance of cross-border patient mobility for the purposes of understanding more than a simple tally of the number of financial transactions as indicators for episodes of care.

Data lying behind the NCP data is often collected by either insurers, healthcare providers, or both- but on different templates which are often derived from internal corporate or organisational requirements – therefore the format, extent, and level of information captured is very subjective and may also constitute a limit to what can be discovered about NCP figures. As indicated by the rich data set collected on care provided in the 25 Lower Austria hospitals, this is based on the needs of the insurer, showing overall numbers, and broad DRG categories. It does not however show where patients live (only where they are insured and what citizenship they hold) nor where they receive care, as the border region aspect is not of particular interest to the insurer, who only wants to know how many people are being treated outside the people for who they provide insurance.

Noting that data on the origins and destinations of patients might be useful for care planning, respondents emphasised that in functional and operational terms, those with the job of data collection are not always those involved in organizing the pathways for patient mobility. You can intervene and close gaps in data but you need a reason to do this- there is no point in data without mobilization.

The healthcare sector in Europe, at a clinical level, is moving towards the concept of 'improvement collaboratives' as a model for improving outcomes for patients and

ensuring high-quality services based on best use of existing resources. Good data, within a clinical services environment, is always key to service improvement cycles and the clinical healthcare services sector is culturally acclimatised to working with system statistical data as a matter of routine.

While there is no current 'data collaborative' approach running alongside the extensive degree of clinical and service access cooperation in this case study region, there may be the opportunity for stakeholders to work together to identify common data sets within what is currently captured, and also to identify desirable data sets as a first step to agreeing a common data capture framework for cross-border patient mobility. As well as being an opportunity for this case study region, this issue is further explored in the context of overall general conclusions and recommendations of the study.

The infrastructure for overall cooperation in healthcare exists already in the region, and a data component to the well-established arrangements might stimulate further developments of actions to meet the needs of the cross-border population. Within this wider context and purpose which has meaning for the values of the main actors in cross-border health cooperation, there is the possibility that better data on the use and uptake of reimbursement mechanisms could be achieved on a methodical and recurrent basis. Data collaboration to close gaps in data, undertaken in the context of a region such as this one, would not be 'data for data's sake' but could be incorporated as a technical and essential element of wider collaboration for the benefit of patients and to inform future service planning. Within the context of a data collaborative for the region, both regional and national actors from each of the jurisdictions involved could find a basis for further innovative collaboration leading to efficiency in resources combined with optimal outcomes for patients- particularly but not exclusively those in immediate border areas- noting that some of the services already accessed within the Healthacross catchment are accessed by patients from further afield who have made the decision to travel for care quality reasons.

What are the future possibilities for cross-border patient mobility in the region/what are the dependent factors for this?

A range of possibilities were indicated by stakeholders in relation to future possibilities for cross-border patient mobility in this case study area. These are summarised as follows:

- It was indicated that with additional cooperation with the neighbouring cross-border region, additional cooperation in the area of Pulmonary Cardiac Thoracic Surgery could be explored.
- Mental health, psychiatric and dementia care are a growing need and further cooperation could be developed between care providers in primary and secondary care to meet the emerging needs of the cross-border regional population. It is noted that not all of this care would fall within the scope of the Directive but it is nevertheless an important aspect of the population's needs and there is a will to explore ways of responding to these needs on a cross-border basis.
- Additional cooperation by care providers and clinicians would also be desirable in the area of chronic diseases management, including support for patient self-management.
- There is also scope to look at how regional assets could be mobilized on a

cross-border basis- again to meet the needs of the population and deliver care closer to home for patients- in the areas of rehabilitation and remobilization of patients.

- In relation to maternity care, it was stated that a dream for the future would be long-term cooperation on neonatal and paediatric care. In Austria, Giesterbach is the closest neonatal unit in Austria, about an hour's drive. There are closer neonatal facilities directly across the border in Slovakia and to find ways of co-operating to make these available cross-border would enhance both clinical, social, and emotional outcomes for patients and their families.
- It was also indicated that further cooperation on elective care provision could be explored on a cross-border basis as a response to the impact of COVID-19 on waiting lists. It was suggested that this exploration could involve initial discussions between insurers and Healthacross and it is intended to put key stakeholders in contact with each other- Healthacross could assist with facilitating this work.
- As regards multi-level governance for cross-border cooperation at the level of and between Member States, through bilateral agreements, it was stated that there needs to be another state-level agreement between Austria and the Czechia on shared approaches to care, similar to that which both Member States have already put in place for emergency care. This is a basic requirement for all future care cooperation and will enhance the potential of local arrangements via Healthacross. Such an agreement should cover all types of care, allowing those healthcare providers and other stakeholders to then work to the maximum scope of what can be offered to the population across all areas of clinical need.
- The NCP expressed an interest in exploring further cooperation with Healthacross in general terms and specifically in the area of collaborative approaches to both patient information and data on use of the NCP information service.
- There was a general consensus amongst stakeholders that there is no point in data without mobilization and that you need a context and purpose for closing gaps in data- stakeholders further expressed a desire to work together on this.
- The NCP would find data useful on important patient flows and gaps in data/benchmarking data- not only for self-evaluation purposes but also to look at future opportunities for approaches to cross-border care- i.e., future collaboration for patients.
- Further work is required in relation to insurers' approach to reimbursement and tariffs- more needs to be done to ensure that pricing structures and reimbursement procedures enable the patient to access their rights under the Directive- at present, the arrangements mean that for example a Czech patient will be reimbursed far less for treatment in Austria.
- The role of patient financing mechanisms must be looked at in the future to remove the burden of cost from the patient in accessing their rights under the Directive.

What would better data do and who is interested?

There was a general consensus amongst respondents that there is interest in better

data at the level of the region and at the level of the NCP, in all three constituent countries. All stakeholders involved in the research, including insurance bodies both public and independent sectors, expressed a willingness to participate in discussions. A significant observation was that the AEBR Focus Group was the first time that a number of key stakeholders working variously at national or regional level had met. Interest was expressed by stakeholders in developing links with each other for the purposes of exploring possible further cooperation between national and regional levels, in the context of cross-border patient mobility data, information to patients, and clinical collaboration.

What impact has COVID-19 had on cross-border patient mobility in the region?

The survey results suggested varying views on the impact of COVID-19 on patient mobility across borders in the case study region. Those involved in delivering coordinated cross-border care may have noticed fewer numbers of patients crossing the border to Austria for care. The view was also expressed that in addition to fewer patients crossing the border for care (focus group discussions indicated that this was partially due to disruption of existing arrangements for mobility and patient transfer caused by blanket closure of national borders during a series of intermittent full lockdowns over an 18-month period), waiting lists have increased in-country. While these findings are essentially impressionistic, they chime with a general awareness across many Member States that waiting lists for planned care have increased and are likely to remain a challenge for health systems in the context of post-COVID-19 recovery.

Focus group discussions raised the following points as regards the impact of COVID-19:

- All projects where patients needed to cross the border were impossible.
- There are standing agreements on emergency care cooperation but emergency services could not cross the border.
- The impact of this was that patients had to travel potentially further within their country for emergency treatment.
- There are many Czech workers in Lower Austria hospitals. Hospitals depended on worker mobility.
- Lower Austria did however offer ICU support when neighbouring hospitals did need overflow but in-country. Patient transfers were extremely difficult nigh impossible cross-border.
- The impact of COVID-19 on the healthcare workforce was chaotic- essential workers were not always provided with border passes in the first lockdown and many carried overnight provisions with them in case stranded. By the second lockdown, this had been addressed. A lot of solutions were in place after the first 1/3 of the lockdown period.
- Communication with local authorities was via Emergency Planning Committee.
- Health Across has data relating to waiting lists, but for Austria only.

3C.6 Analysis

It is clear that there is a level of capacity, cultural and intellectual capital for a territorial/regional approach to shared healthcare services and collaboration in the Lower Austria/Bohemia/Slovakia case study region covered in this chapter. Healthacross has had a very specific focus on patient care provision by Gmünd hospital and other hospitals serving the cross-border area.

It is also clear that while there is a body of data collected, the extent to which this can provide a consistent level of information on the nature of cross-border patient mobility statistics is limited in the current circumstances. However, the relationships exist for a more systematic and coordinated approach to development of a common agreed and shared data collection framework which can not only serve to inform NCP reporting on patient mobility at national level but can also serve to further underpin with good quality evidence the ongoing collaboration and co-designed approach to provision of cross-border health services to the patient catchment of the cross-border area.

This case study demonstrates the matter of the East/West divide that exists within the EU as regards a general variance between East and West relating to healthcare costs, and the role which prior authorisation has to play in the extent to which patients travelling West for care can fully access their rights. In addition, there is a desire at the level of Healthacross- in keeping with the EUREGHA/Healthacross recommendations referenced in the overall literature review for the study - which relate to the need for innovative financing mechanisms to be developed which are patient-orientated. In this case, we refer to the example of the social finance model developed by the Irish Credit Union movement (specifically Derry Credit Union) which assisted with pre-financing supports through interest-free loans, and subsequent recoupment via reimbursement, for patients seeking care under the Directive on the Ireland/Northern Ireland Border. Healthacross have expressed an interest in understanding this model and information and contacts will be shared via AEBR as a follow-up action.

3C.7 Case-Specific Recommendations

The case-specific recommendations arising from this case study are as follows:

1. Building on the connections made between national and regional stakeholders through the AEBR/DG SANTE Research, a collaborative for data and planning should be formed which includes key regional actors such as Healthacross, clinicians, hospital senior management, and the NCPs from the three constituent Member States relevant for this cross-border patient catchment region. Given the existing links with WHO Europe, it may be an opportunity to also involve representation from WHO Europe in a data collaborative which focuses on more detailed patient mobility statistical data as a subset of wider data on the health needs of the cross-border patient catchment denoted by the sphere of influence of hospitals currently operating in the region.

2. This collaborative should look at the prototype data capture template proposed by AEBR as a research tool, and examine ways in which all parties may be able to work collaboratively to make small innovations in internal data collection arrangements, in order to provide data which can populate the suggested template. This process could be applied to, for example, a subset of the 2018-2020 Patient Mobility data to identify ways in which prospective data collection could be 'tweaked' or designed by data partners to fit with an improved data collection template which not only meets the needs of the partners collecting it but will contribute to a greater sum total of

data that can inform further collaborative and value-adding action by the members of the collaborative.

3. Healthacross, its partners, and the NCPs should meet to explore how they may be able to work together on the specific process of patient information and awareness, and how symbiotic processes could be developed which allow for dissemination of patient information through regional and local channels, to complement information provision at the central NCP level.

4. The partners who participated in the AEBR Research should consider maintaining a strategic forum of NCPs and regional actors with an interest in supporting, facilitating, or monitoring patient mobility in the cross-border region, as a strategic engagement action which can benefit the business processes of all actors. Relationships between the region and central government actors reporting on patient mobility and responsible for implementing the Directive should be nurtured for the benefit of all.
5. Specific consideration should be given to the role of the Directive in addressing post-COVID-19 demand for planned care in the region, and whether there are other interventions that might be required in order for a regional cross-border approach to COVID-19 recovery of the regional health systems to be successful.

6. Healthacross and partners in the region should consider how the EU Digitalisation and 'Smart Regions' Agenda could inform the approach of a data collaborative for the region, and link with regional cross-border territorial cooperation actors and other relevant policy stakeholders in this regard.

7. Clinicians working to support cross-border patient catchments in the region should be given the opportunity to view best practice across other EU border regions where shared clinical service pathways and models have also been developed. Consideration should also be given to further engagement of primary care and population health promotion actors in the Healthacross region in the uptake and use of any new, more complete data generated by a proposed data collaborative.

3D Case Study 4 – Poland/Czechia

3D Case Study Table of Contents- Poland/Czechia

Poland /Czechia	**Summary of Findings - Key aspects of cross-border patient mobility** **Key players:** NFZ (Polish insurance fund) NCPs, local clinicians, cross-border care agency (private enterprises) **Sources of information:** National Contact Points, key clinicians, responses to questionnaire, 2020 Annual Report on Directive, 2020 Annual Report on Regulations (both citing 2019 data)
***Who** are the key players?* • ***Who** uses care?* • ***Who** informs care?*	•The national insurance contact points in the regions provide information to patients, in addition, private enterprises operate which support patients in accessing care in other countries.
***What** cross-border care is accessed ?* • ***What** types of care are accessed?* • ***What** influences patient mobility?*	• NFZ received 940 requests for information in 2020, however, they reimbursed 6513 patients, suggesting the NFZ is not a key source of information about cross-border care. • NFZ reported that of the 6513 patients reimbursed nationally 5514 patients obtained care in Czechia, and of those 2,736 live in the three provinces which border Czechia. Czechia is, therefore, the main choice for cross-border care in Poland, even for those not living in the border region. Of the 6513 patients reimbursed in Poland, 4838 were for cataract surgery.
How** is cross-care reimbursed?* • ***Regulation • ***Directive*** • ***Other***	Czechia and Poland did not report issuing any PDS2s for care in the other country, nor any receipt of PDS2s from the other country. Czechia made 916 reimbursements for planned care under the Directive in 2019, of which the majority (539) went to Germany, only 17 reimbursements for care in Poland were reported. Poland reported 15,574 reimbursements of which 14,171 were for care in Czechia Poland reports that it operates a parallel national system for care in another country, and on the basis of national legislation sends patients for planned medical treatment abroad, if the treatment is not performed in Poland, but the treatment is necessary for the patient in his/her health condition, and the treatment is included in the medical services provided for by the legislation of Poland. Such treatment may be provided by public or private healthcare providers. Poland was able to provide very detailed data on border region mobility as shown above,

Summary of Findings -Qualitative Conditions for Cross-border Patient Mobility	Key Actors	The Future	
Poland/Czechia  	**NCPs** **Health Economists and Research Institutions** **Polish specialist agencies (patient mobility)** **Rare Diseases – patient representative organisations**	**More research to analyse legal and economic obstacles to cross-border patient mobility** **Research collaborative led by Charles University (Votapkova et al) to analyse obstacles and create an evidence base** **Place-based collaborations between hospitals on the border (Sluknov region)** **Explore innovative pilot actions for patients with rare diseases through regional partnerships/AEBR**	**Specific attention to patients on borders?** **Cross-border approaches to planned care post-COVID-19?** **Exploration of partnerships on the Czech-German border?**
Proximity matters in patient-centred care- for many the nearest point of care is across the border	**Patients with rare diseases need better access to information and reimbursement for cross-border care (beyond diagnosis)**	**Independent, well-coordinated information for citizens in their own language**	**Improve response time by insurers to patient requests for information and reimbursement**
Low levels of patient mobility from Czechia- barriers to mobility – pricing information, patient awareness of the right to travel	**Multidisciplinary care abroad for rare diseases is a quality choice for patients**		

3D Case Study 4 - Poland/Czechia

3D.1 Context for Cross-border Patient Mobility in the Case Study Area

The context for this case study differs from the other three case studies in this initiative in that the focus for research was not a specific cross-border region or functional area, but a general country-to-country patient mobility flow-focusing primarily on patient mobility data for patients from Poland accessing care in the Czechia. The rationale for inclusion of a country-to-country case study of this nature, alongside a more regional and territorial focus of the other three case studies conducted by AEBR on behalf of DG SANTE, was the evidence from 2015-2017 official patient mobility figures reported to the European Commission that showed a high degree of patient mobility from Poland to Czechia.

In this context the data discovery research focused on data held by NCPs and insurers- in the case of both countries, the insurers are national public health insurers.

The qualitative research conducted as part of this case study did, however, reveal other vignettes relevant for cross-border patients from Czechia– mainly in the case of cross-border patient mobility of Czech patients to Germany. The study also revealed some considerations specifically relevant for Czech patients with Rare Diseases in accessing care in Germany.

Beyond the specific data discovery research undertaken with NCPs and insurers, the nature of the qualitative data in this case study was experiential and from the perspective of respondents who spoke to either place-based or individual experience of cross-border care access issues associated with patient mobility. It is hoped that the insights provided may go some way to stimulating next steps in relation to one or two specific pilot activities which can address some of the finer points of patient rights in the context of the patient mobility possibilities which are technically conferred on citizens through the legal mechanism that is the Directive.

3D.2 Member State Health Systems

This section provides information on specific provision by the health systems relevant for the case study. The European Commission's Health at A Glance report[87] is produced annually in cooperation with the OECD and the European Health Observatory for Health Systems. It provides high-quality and in-depth information on Member State population health status, risk factors, health system performance reporting, and analyses developments in overall healthcare system resourcing and administration for each Member State. In understanding the key features of the various health systems in the Member States relevant to the case study areas, the

[87] Country Health Profiles | Public Health (europa.eu)

French Government's *Cleiss*[88] website also provides information fiches for countries globally which focus on information on types of healthcare provision in-country.

The Health system features for the Member States relevant to our case studies are summarised as follows:

The Polish Health System:

The health system is decentralized and the management and financing functions of the Polish health care system are divided between the Ministry of Health, the National Health Fund (NFZ) and the autonomous governments of the regions.

The universal health care system covers all citizens, regardless of their financial situation, and they are entitled to equal access to publicly funded health services. The vast majority of the population is covered by the compulsory health insurance system, including family members of contributors and certain vulnerable groups whose contributions are funded by the state budget. In addition, the legal framework of the system is based on the law on publicly funded health services and the law on therapeutic activities as well as legislation harmonising Polish law with that of the European Union.

Individuals insured under the NFZ are entitled to a very wide range of health benefits. With a few exceptions for reimbursement of medicines and medical devices for which privileges are granted to certain groups (disabled and military veterans, blood and organ donors), in the form of exemptions and/or reductions of the moderating ticket, the legislation does not distinguish between the different groups of insureds with regard to the extent of benefits. This list includes:

- primary health care (internal medicine, emergency medicine, family medicine),
- specialized outpatient care,
- hospital treatments,
- state-of-the-art hospital treatments (e.g., transplants),
- psychiatric care and addiction treatment,
- therapeutic rehabilitation,
- nursing and long-term care,
- dental treatments,
- spas,
- Pharmaceuticals,
- orthopaedic medical devices,
- Emergency relief,
- palliative care,
- preventive care.

[88] Centre des liaisons européennes et internationales de sécurité sociale

Benefits are fully covered by the NFZ and the share of remaining expenses for patients is limited under legal insurance with the exception of medicines and medical devices, as well as spa treatments and certain dental procedures and materials, long-term care, and rehabilitation care.

3D.3 Baseline Data – Member State Data[89]

The data provided by Poland and Czechia in 2019 for the annual reports to the European Commission on the operation of the Directive and the Regulation are shown below. They indicate that Czechia does not operate the prior authorisation system provided for in the Directive, accordingly 'no applicable' is noted in the table. Poland does operate this system, but the table below indicates '0' for Poland because in 2019 no such authorisations were granted, despite the fact that 18 requests were received. The national insurance fund reported that the 18 applications received were sent back to the applicants because they lacked formal data which rendered the assessment of the application impossible. These applications were not re-submitted, and accordingly, they were classified as rejected.

With regard to patient mobility in Czechia, it is worth noting that the total number of reported reimbursements under the Directive in 2019 was 916, of which 539 were for care in Germany and 197 in Austria, there were no cases of reimbursement of care in Poland. In the case of Poland care in Czechia accounted for 91% of all care reimbursed under the Directive in Poland (14,171 of 15,5740.

Table 1- Reported issue and receipt of PDS2 forms in 2019- Poland and Czechia

	Issued	Received
PL & CZ	0	0
CZ & PL	0	/

Issued = number of PDS2 reported as issued by competent MS
Received = number reported as received by treating MS from competent MS treatment in treating MS
NOTE: this number is not always the same, indicating reporting variability.
/ = data not provided
0 = no reported PDS2

Looking at patient mobility under the Regulation, it is clear that the citizens of neither country make use of the Regulation to travel to their neighbouring country for healthcare, this is indeed also true of the wider figures, as Czechia reports having issued 168 PD S2s in 2019 and Poland issued 58.

[89] Data report on the application of the Directive in EU countries (2019)https://ec.europa.eu/health/cross_border_care/overview_en

Table 2 – Reported Reimbursements under the Directive in 2019- Poland and Czechia

	With PA	No PA
PL to CZ	0	14,171
CZ to PL	n/a	17

/ = data not provided
0 = no reimbursements made
n/a = PA system not implemented

Poland reports however that it has its own parallel regulations and, on this basis, sends patients for planned medical treatment abroad, if the following is confirmed: the treatment is not performed in Poland, the treatment is necessary for the patient in his/her health condition, and the treatment is included in the medical services provided for by the legislation of Poland. The above treatment may be performed also by private healthcare providers. These arrangements exist in parallel to the rules on reimbursement implemented on the basis of the Directive and EU Regulations on coordination on Social Security and are used more often.

Complementary data gathered by DG REGIO[90] which also provides context for patient mobility in Poland and Czechia is summarised as follows:

3D.4 Data Discovery Findings – What is known about patient mobility in the case study area?

Interviews with three employees of NFZ (Polish insurance fund) were conducted to gain a better understanding of the reported figures for patient mobility under the Directive. Beginning from the data on requests for information about reimbursement for care under the Directive, it was reported that the three offices serving the three voivodeships (or provinces) in the Polish Czech border region: Dolnośląskie (Lower Silesia), Polskie (Opole) and Sląskie (Silesia) received 940 requests for information in 2020.

This represents a sizeable portion of the 2489 inquiries made in total across all NFZ offices in Poland.

In 2018 the total number of requests received was 24,233, and in 2019 it was 10,192. With the number for 2020 reported as 2489, we see a steady and very significant decline in requests for information over the past three years. NFZ had not

[90] Poland - https://op.europa.eu/en/publication-detail/-/publication/2ef4577e-0bf9-11ec-adb1-01aa75ed71a1; Czechia -https://op.europa.eu/en/publication-detail/-/publication/4c13fae0-0bfa-11ec-adb1-01aa75ed71a1

collected any data on why this decline had occurred but speculated that it is probably related to the awareness of the population, with general awareness of the population regarding the services being higher and thus making additional enquiries redundant.

In contrast to the decline in requests for information, the number of cases granted reimbursement rose from 13,499 in 2018 to 14,171 in 2019. In 2020 however, the total number of reimbursements made under the Directive dropped to 6513. The respondent commented that this significant drop could have been as a result of reduced travel due to COVID-19, but that this was not officially recorded data.

NFZ routinely collects detailed information on the type of care provided under the Directive and was able to share the following very interesting figures with the study:

Of the 6513 patients that were reimbursed in Poland in 2020 under the Directive, 5514 were for care delivered in Czechia, these were all cases for which no prior authorisation was required.

Care reimbursed under Directive in 2020	6513
ophthalmological	4838
dental	745
urology (f)	423
General surgery	153
Urology (m)	121
orthopaedic	90
ENT	84
Paediatric surgery	29
Obs/gynae	10
Cancer (diagnosis)	6
neurology	2
Cardiac	1
gastroenterology	1
psychiatric	1
Other	27

The majority of cases were for ophthalmological care, which NFZ confirmed was for cataract surgery and related procedures, they confirmed also that all the 4838 cases were provided in Czechia. They also clarified that in the case of dental care, the majority of cases pertain to treating people with moderate to severe disabilities. In the case of general surgery, it is mostly patients in need of treatment of varicose veins of legs. NFZ was also able to clarify that 5609 of the cases shown in the table were in-patient treatments, although it was not possible to identify if these were single day in-patient cases or entailed longer hospital stays.

NFZ were able to confirm that 50% of the reimbursements made under the Directive in 2020 were made by the Regional Branches bordering with Czechia, that is the dolnośląski (Lower Silesian) branch, śląski (Silesian) and opolski (Opole) branches. These branches made 3241 of the 6513 reimbursements, that is, half of all the reimbursements made nationally.

3D.5 Qualitative Research Findings

Mobility and Reimbursement Issues

Patient stakeholder organisations and NFZ made reference to the existence of agencies specialising in organising care for certain procedures, such as cataract removal, and that these organisations play a major role in providing information about the potential use of the directive. It was also noted that general practitioners and some hospital departments also provide information to patients and may for many be the first port of call for such information.

NFZ confirmed that the possibility of receiving cross-border healthcare which is funded according to internal rules rather than through the Directive or S2 route. The costs of this treatment are covered based on invoices provided by service providers abroad. However, in such cases, Previous Authorisation is issued according to internal national regulations. NFZ noted that new tools are being developed to facilitate data collection on cross-border care, but that broad terms they felt they had sufficient information for internal needs.

Additional Observations

What influences a patient's choice/decision to travel for care?

It was suggested that there needs to be more closely focused work in specific border regions of Czechia on how the Directive may impact on patients seeking care across national borders. Little research to date has been conducted in the areas of key information useful to patients- for example, information on pricing structures for care. There is also little evidence of territorially focused approaches to shared services or structured inter-hospital cooperation in border areas of Czechia- however, some capacity is developing around this which should be supported in order to develop the necessary cross-border enabling processes for patient mobility which have been developed in other regions such as Meuse Rhine, Grand Est, and Lower Austria.

In the case of patients with rare diseases in Czechia, patients will choose on quality factors to travel to places where post-diagnosis care is integrated and multidisciplinary- this is not currently the case in Czechia. (This point and others made in this case research, on the issue of patients with rare diseases/chronic conditions and persons with disabilities accessing cross-border care, are borne out by the IF Study on the Impact of Cross-border Healthcare on Persons with Disabilities and Chronic Conditions.[91] The rare diseases network is a clinicians' reference network which focuses mainly on diagnosis and clinicians sharing specialist knowledge within virtual collaborative arrangements. However, and importantly, as regards patient mobility for Rare Diseases patients, and particularly given that RDs are lifelong conditions, patients still need to be supported to travel post-diagnosis to receive the best possible care and to have a choice about their care.

From a patient perspective, for patients with Rare Diseases wishing to access cross-

[91] IF/EDF/EPF (2016): *Impact of cross-bord**er** healthcare on persons with disabilities and chronic conditions.*

border care, while diagnosis and clinical treatment are essential, so too- and particularly important for patient outcomes over time- is the degree to which the patient and carers/family are supported in management of the disease. In Czechia, apart from the efforts of patient advocacy organisations for Rare Diseases who make some effort to support patients and families around Rare Diseases, this patient group lacks the information about choices for travelling for care cross-border under the Social Security Regulations and the Directive.

Mobility across borders of patients with rare diseases for post-diagnosis treatment is dependent on recommendation/consent to refer from a doctor in-country. Clinicians do not always like to recommend that the patient goes somewhere else-and thus the decision not to refer may not always be made in the best interest of the patient.

Sometimes patients have to use lawyers to get approvals for reimbursement of care under EU legal mechanisms and it is difficult- places a great financial and psychological burden on patients and their families who are already struggling with so much.

Some treatments for rare diseases are available in Czechia, others not. Where not available in-country, patients are extra motivated but still have to fight for the right to travel. The impact of this additional psychological stress on patients and their carers is considerable and affects their overall health.

There are multiple barriers to cross-border patient mobility for patients with rare diseases in Czechia - these range from difficulty in getting the support of a treating clinician for a referral abroad, to difficulty in easily getting access to reimbursement of costs.

As regards other types of care where cross-border patient mobility may be in the best interests of the patient, one patient described asking for Prior Authorisation under the Social Security Regulation to give birth in a German hospital ten minutes across the border from her home in Czechia. Prior Authorisation was refused but the patient was told they could use the Directive. However, the German hospital which the patient wished to attend did not accept patients travelling under the Directive because of a history of patients not paying charges levied in line with the Directive requirement for patients to pay upfront and then claim reimbursement through their insurer. The Patient got clinician support for a subsequent birth to take place in Germany on the basis of clinical recommendation, but in this case, the healthcare insurer took two months to reply to the patient's information request regarding reimbursement. Additionally, when the burden of paperwork is on clinicians in the context of reimbursement by an insurer, clinicians are averse to dealing with the documentation.

Patient perspectives offered suggest that in the case of Czechia, when the Member State feels that everything can be offered within the national borders, the answer to a request for authorisation to travel cross-border for care is by default a no- this disadvantages people in border regions and also patients with rare diseases.

The point was also made that while, on paper, certain areas of a country may lie within a standard access time to an in-country hospital, often seasonal weather conditions and topography place the access time at the very outer limits of the requirement at best- one area of Czechia involves a minimum 50 minute travel time to the nearest in-country maternity unit and in winter this can be much longer as the journey involves crossing an extremely mountainous area which can at times be impassable. This presents patient safety risks as well as potentially adding to distress for patients in vulnerable conditions. In this sense, geographical distance to in-country services cannot be the only factor used to determine whether or not a

patient can access services across the border.

As regards the reasons why Polish patients travel for care, it has been emphasized that Polish patients travel mainly for ophthalmology and because in Czechia there is a free choice of lens whereas in Poland the patient cannot choose the lens.

There is a degree of organized healthcare tourism from Poland to Czechia, where patients- particularly patients with disabilities from border regions- travel in groups to receive care. This applies in particular to dental services for people with disabilities because the associated Czech anaesthetics services are perceived as being better and more appropriate to patient needs- full anaesthesia is required in many cases and this is not always available in Poland.

Language is a factor in the choice of Czechia-based services for some Polish patients, in that Czech clinics on Poland/Czech border usually have Polish-speaking personnel. It was emphasized that the numbers going from Czechia specifically to Poland are lower due to language issues.

How do citizens in the case study area get their information on cross-border healthcare opportunities?

Citizens in the case study area can obtain information from the NCP websites. Specific patient advocacy organisations, particularly in the case of patients with Rare Diseases, also provide information on cross-border healthcare opportunities. However, more needs to be done to make patient information accessible and research is needed to establish useful sets of information that can assist patients in making informed decisions about cross-border healthcare.

What role do health insurance providers play in facilitating cross-border patient mobility in the region?

The national health insurance funds are regionalised and are able to provide information to patients. However, the reports provided by the respondents from NFZ, as well as patient stakeholders, suggest that specialist agencies and some groups of medical specialists are the primary route both of information on cross-border care, and on support for accessing such care. This would seem to be the case particularly dental and ophthalmological care, which account for the majority of care reimbursed under the Directive.

The fact that an alternative internal system exists is interesting and may suggest that the national insurer is actively facilitating access to care abroad, but as limited information is available on this system it is hard to assess its impact and role.

Qualitative perspectives in this case study highlighted the crucial role played by insurers in facilitating patients' access and as arbiters of a patient's mobility insofar as prior approval for costs of care was usually sought by patients to prevent a situation from arising where care costs would not be reimbursed.

Why are there gaps in data on cross-border patient mobility?

While discussions with NCPs focused and are reported in more detail on the issue of data gaps, additional qualitative perspectives were offered in relation to this question, which points to considerations associated with on-the-ground arrangements for cross-border patient mobility and the operations associated with

these. One perspective offered was that there is often a low level of admin support in receiving care centres and referring centres- the administration associated with individual episodes of care is often left to clinicians and this takes up patient time. Another perspective offered was that there is an absence of systematic facilitation of cross-border patient care which might, if addressed, provide a context for better data- even if it were to be specific and confined to a specific territorial area.

What are the future possibilities for cross-border patient mobility in the region/what are the dependent factors for this?

In the context of this study, what was revealed was a lesser extent of utilisation of cross-border care possibilities at the level of specific geographical populations along borders. Research respondents observed that the same regulatory framework produces different results depending on regional and local capacity to give meaning to national translational arrangements for implementation of legislation such as the Directive. This issue, unaddressed, is also a major factor in data gaps.

However, Charles University Department of Health Economics is developing a proposed research initiative led by Dr Jana Votapkova, and with the participation of the Czech NCP, which will identify baseline data relating to cross-border patient mobility and conditions for this mobility between Czechia and Germany. Part of the action research element of this project will be to lay the groundwork for a cross-border patient care pilot with several German hospitals adjacent to the Sluknov border region of Czechia. The research will also focus on the specific rights of patients in border regions and examine both EU and domestic legislation to determine the precise scope of legal frameworks in which the issue of patient rights in border regions needs to be located. The research proposal addresses the following:

Research Proposal: Cross-border cooperation in healthcare provision between Germany and the Czechia: analysis of legal and economic obstacles

Summary of research questions and proposal:
Research areas:

1. Detailed legal analysis of European and Czech legislation defining reasons why neither Czech nor European legislation does represent the legal base for the inhabitants of border areas when receiving acute health care across borders. We aim to suggest necessary changes to the legislation and suggest a legal document that would make cross-border healthcare in border areas possible.

Outputs:

A) Legal analysis
B) List of suggested changes to legislation

2. Specification of the types of hospitalizations, the content of which is similar in both Czechia and Germany. Set up methodology of calculations of price differences for these model hospitalizations in the Czechia and Germany as model countries. Price differences will consequently be calculated also for hospitalizations with less similar content. We expect this methodology to be applicable for other types of hospitalizations in other border areas, not just CZ-DE.

Outputs:

A) Methodology
B) Publication in a reviewed journal

3. Identification of legal issues that may arise and suggest their solutions once cross-border healthcare is already in place. A methodology will be set up which both providers and patients will be able to actively use.

Outputs:

A) Methodology
B) Guide to patients and providers that they could actively use

4. To identify a list of future steps that will have to be carried out to start real provision of cross-border healthcare at the Czech-German border (Sluknov area)

The research team for this proposed work consists of the following experts:

PhDr. Jana Votápková, Ph.D. (Institute of Economic Studies, Charles University in Prague, CZ)
Anne Spranger (TU Berlin, Observatory for Health Systems and Policies)
Doc. Martin Gregor, PhD (Institute of Economic Studies, Charles University in Prague, CZ)
doc. Paola Bertoli, PhD (Institute of Economic Studies, Charles University in Prague, CZ, University of Verona, Italy)
PhDr. Adam Ander (Health insurance bureau – Kancelář zdravotního pojištění)
MUDr. Pavel Hroboň, MS.C. (Advanced Healthcare Management Institute, Prague, CZ)
PhDr. Blanka Čermáková (Advanced Healthcare Management Institute, Prague, CZ)

It is proposed that additional healthcare providers will be consulted as follows:
MUDr. Ivan Sucharda (Czech Medical Chamber)
MUDr. Václav Jára (Director of Varnsdorf hospital)
Asklepios Säschsische Schweiz Klinik Sebnitz
Klinikum Oberlausitzer Bergland, Ebersbach-Neugersdorf

Additional Possibilities to support patient mobility in the case study area:

It was also suggested that, given that some patient mobility is affected by existing emergency services protocols or restrictions in emergency services protocols as regards vehicles crossing borders, further work needs to be done in the development of Memoranda of Understanding in geographical border areas where this will enable a better and safer level of service to be offered to the population on both sides of a border.

There is also potential to explore a pilot project on patients with rare diseases from Czechia accessing care in Germany- which would look at the specific issues for the patient group with regard to patient information, reimbursement, negotiation with insurers, and eligibility of costs integral to the successful delivery of care and positive health outcomes for patients with Rare Diseases. It has been suggested that AEBR will separately liaise and help to facilitate options for progressing such a pilot in

connection with relevant member regions, Charité hospital in Berlin, and Czech rare diseases patient advocates. There needs to be further exploration of the role of local/regional bilaterals for specific groups for whom care accessed in other countries is vital, and rare diseases communities should be part of this in order to access their closest centre of expertise.

In progressing possibilities for patient mobility, the subnational agency of actors is essential. So too is the development of approaches which allow for pilot initiatives to be shaped through patient perspectives- patients who access both systems have insight into how things can be improved at home. This is a particularly important point in that patients accessing care abroad should not be seen as a threat to a domestic health system, but rather a valuable asset whose perspective can help to improve care at home. In this sense, the qualitative patient experience data of patients travelling for care- when decision to travel is based on perceived and actual better quality of care- can and should be gathered by Member States to inform improvements at home. Quantitative patient data can also be used to assess demand in-country and can be useful evidence to inform adaptations or improvements in domestic provision and availability of services for which patients otherwise have to travel – as in the best practice demonstrated by the Polish Ministry of Health in increasing provision in-country based on assessment of demand from data on patient mobility for particular procedures.

Future possibilities should also ensure consideration of investment- in the context of geographical and patient group pilots- of enhancing healthcare administrative baseline to support the paperwork associated with receiving and/or referring patients abroad.

Specifically, for patients interested in clinical trial participation (particularly relevant in the case of patients with Rare Diseases where speciality research may be concentrated in a particular centre of excellence in another EU country, there should be more opportunities for patients to participate in clinical trials across borders- in keeping with European Disability Rights and Equality principles, Member States should see the Directive and regulation as useful tools to enable as many options as possible for patients and treating clinician to get the best possible outcomes for patient quality of life and that of carers/families.

What would better data do and who is interested?

The national insurers have stated that they are happy with the data they collect and have access to, and do not see the need for any further data to be collected. Patient groups however shared frustration with the transparency of the system and could benefit from more targeted patient focussed information. This is particularly the case for patients with rare diseases. More data collection needs to be done in conjunction with transboundary cooperation on service improvement for patients with complex needs.

From a research perspective and to inform the development of area-based pilots e.g., Czech German border, more data on reasons for refusals of cross-border reimbursements or requests for prior authorisation would be useful.

3D.6 Analysis

This case study focused on the issue of patient mobility data and has produced what findings were possible in that regard. Patient mobility data is one indicator of the

state of patient mobility arrangements. To merely concern ourselves with existing data does address the matter of data but does not address the context of full implementation of the Directive- and so the route to better data may be through a process which enables subnational and regional actors to create and develop conditions for informed choices by patients, to travel- and informed decisions by Member States as to where evidence of demand can create momentum for domestic improvement.

In terms of regional cross-border cooperation, the iterated focus on data in this case study may have caused stakeholders to self-exclude who were more focused on general cross-border cooperation. Therefore, it is emphasised that further dialogue involving regions and cross-border patient mobility – particularly involving Polish and Czechia border regions may be possible within the context of AEBR and may be useful for AEBR member regions to pursue as a separate action following the conclusion of this study.

The research has nevertheless revealed a body of considerations which are associated with the enablement and facilitation of cross-border patient mobility as an underlying factor in patient mobility data quality- itself a product rather than an objective of the Directive. It is particularly of note that Charles University has chosen to focus some of its research energies on the health economies of border regions and we note this development with interest as something relevant for the overall EU patient rights and cross-border healthcare agenda. The involvement of the Czech NCP in supporting this research is also to be noted as an example of good practice for NCPs in providing leadership for innovation which will ultimately enhance the implementation of the Directive and Social Security Regulation as regards their impact on patients who have a particular need for cross-border care. This action is entirely consistent with the principle of subsidiarity and is reflective of a general observation throughout our overall research that there is capacity and scope within the NCP role to support and partner relevant activities in this way, where the NCP is more closely interconnected with subnational and regional actors who are willing to work together to deliver on shared objectives.

This case study raises the opportunities which exist for the rights of specific patient groups to be examined more closely as to how the Directive – or other mechanisms facilitating patient mobility- might deliver a more complete version of patient rights through access to mobility for care. Equally, the insights and data relating to patients wishing to travel for care- especially in Czechia- may inspire further work in-country around the provision of targeted information via the NCP to patients who will continue to need to access care abroad on the basis of clinical need and optimising clinical outcomes.

As regards the benefits to Member States of good data on the Directive, this case study also demonstrates the example of where high levels of patient mobility as shown in data- as in the case of Polish patients crossing the border for ophthalmological care prior to 2018- helped to inform an evidence-based approach by the Member State health system to increasing provision in-country. This action led to a reduction in figures of those travelling for this kind of care under the Directive.

For patients travelling to and from Czechia, but particularly those for whom care in Germany is a preferred option, the Czech NCP has a specific birds-eye overview of all

strands of patient mobility, interest in patient mobility, and may be able to make a very positive contribution to activities designed to address the fundamental conditions for cross-border patient mobility at various parts of the Czech border.

3D.7 Conclusions and Case-Specific Recommendations

1. Consideration should be given by policymakers and funders to finding a pathway to support approaches to facilitating cross-border patient care in the context of patient rights and the rights of citizens in border regions- particularly where uptake of cross-border care is low but where the proximity of cross-border care removes geographical barriers to access. A good practice proposal in this regard is the study currently being developed by Dr Jana Votapkova (Charles University):[92]

2. AEBR should explore how it can further assist with and support the progression of some of the future possibilities arising from this case study- particularly through linking the Sluknov regional actors/the research team at Charles University with its Cross-border Health Task Force members and associated organisations. It should also explore connecting relevant INTERREG stakeholders who can potentially support a Czech-German pilot for post-diagnosis multidisciplinary care for patients with rare diseases.

3. The function provided by the specialist agencies which organize certain types of cross-border care should be analysed in order to establish how they can be better integrated into the healthcare system to support patients.

4. There may be additional scope for Czech/German and Polish/Czech collaboration to take place on the basis of responses to elective/planned care waiting lists following the COVID-19 pandemic in the context of the overall recommendations of this study.

[92] Outline of proposed research initiative aimed at building capacity for territorial cross-border interhospital cooperation on German/Czech border. Provided by Dr Jana Votapkova, Charles University (2021)

4.0 Chapter 4 – Overall Findings, Conclusions and Recommendations

This chapter first highlights and comments on overall findings; secondly, it presents overall conclusions and recommendations linked to the key research objectives. Recommendations are focused on future approaches to improved data collection on patient mobility and deal not only with the necessity for this but also suggest methodological approaches involving multilevel stakeholders which have the potential to add value to existing data collection and reporting processes.

4.1 Overall Findings

The original specific objectives of this study were as follows:

1. To gather available data on cross-border patient flows in the case study regions using different reimbursement mechanisms for planned healthcare (Directive, Social Security Coordination Regulations, and other bi-lateral arrangements);

2. To gather qualitative information, where available and feasible, on the types of treatment for which patients seek cross-border healthcare or information on patient mobility within the context of COVID-19 (COVID-19 and non-COVID-19 patients) and of communication on cohesion in border regions;

3. To improve understanding of the methodological difficulties to monitor patient flows, to collect data on the different reimbursement mechanisms;

4. To provide recommendations to improve data collection on patient mobility at EU-level for the purpose of Directive 2011/24/EU (reporting requirements under article 20) and actions which could be taken at regional, national and EU-level.

In this section, our overall findings and recommendations are presented under headings which corresponded with the four main areas of research enquiry set out above.

Study Objective 1: Overall Findings on Cross-border Patient Flows using different reimbursement mechanisms for planned healthcare (and the specific role of the Directive):

Cross-border care is used mainly by people living in proximity of a hospital or healthcare providers located across the border – this is frequently the nearest point of care for patients in border regions, for whom the in-country alternative may involve long journeys and additional care costs (particularly for patients with disabilities and rare diseases);

Many patients living in the border region are heavily dependent on cross-border care, in particular those with chronic conditions who need frequent expert care.

Patients are informed by primary care providers, by insurance information points,

cross-border healthcare partnerships, Euregio structures and other civic representative bodies, and by NGOs focusing on patient rights (citizens' rights, disability rights, rare diseases). In some cases, such as Poland, specialist healthcare mobility agencies also play a role in providing patients with information and facilitating critical mass of patient mobility for specific types of procedure.

There is a strong relationship between high levels of patient mobility where general cross-border mobility is high- such as in the Luxembourg/Grand Est FR region (43% of Luxembourg's workforce comes from across the country's borders).

Cross-border care is most effectively supported and flows are well-established in areas such as Lower Austria where healthcare provider organisations work in a coordinated fashion across borders and also promote awareness of cross-border care opportunities amongst their cross-border patient catchment area.

Within Objective 1: Findings on the role of the Directive within the wider context of Reimbursement Mechanisms

The summary tables for each case study provide additional detail on the full range of reimbursement mechanisms used for cross-border care in key regions. Here we specifically wish to highlight summary findings on the role of the Directive within the context of reimbursement mechanisms.

Patient mobility in border regions depends on two factors- the availability of legal reimbursement mechanisms, and the availability of cross-border patient pathways based on collaborative working between regional health providers, insurers, and citizens/civic institutions.

Overall, the evidence gathered during this study indicates that the Directive- as an important facility for the reimbursement of planned care which has been provided to the Member States in EU Legislation- provides an important ongoing mechanism to meet particular types of patient need for planned care.

The Directive has particular potential significance in border regions for meeting patient needs in this regard and with more collaborative and strategic approaches (such as those suggested in respect of cross-border collaboration on elective care waiting lists Post-COVID-19)this potential can be realised further. This conclusion can be drawn despite existing challenges such as the level of awareness which patients have of the Directive and the ongoing use of other reimbursement routes.

The Directive is understood as a complementary mechanism for reimbursement within a suite of options available to Member States and their citizens- which include the Social Security Regulations and local bilateral arrangements detailed in the case studies. While data gaps remain (and may be addressed in border regions through the implementation of some of our recommendations), nevertheless the evidence we have gathered on use of the Directive indicates that it continues to be an important vehicle through which patient choice can be facilitated. This is particularly so when use of the Directive is underpinned by well-organised and well-informed cross-border patient care pathways accompanied by transparent and pro-active patient information provision.

The study also highlighted an awareness of a potentially emerging role for the Directive in addressing rising demand for planned care in the context of pandemic legacy and waiting lists, and the potential for combining the Directive as a reimbursement mechanism with more intensive, place-based cooperations- particularly in border regions- for providing much-needed planned care to patients on a cross-border basis.

Within Objective 1: Specific data findings on cross-border patient flows under the Directive in the case study regions:

Meuse Rhine Region: Germany, Netherlands and Belgium were not able to provide data on reimbursement under the Directive for care not requiring Prior Authorisation (PA) citing lack of capacity to collect data in a uniform way from the many insurance providers in each country. Only Belgium was able to report mobility based on Prior Authorisation (PA), reporting 6 cases. The Netherlands does not operate a PA system. The Dutch health insurer CZ separately reported having reimbursed 852 episodes of care in Germany for its insured patients across the Netherlands, under the Directive in 2020.

Grand Est (FR)- Luxembourg: France reimbursed 13,235 care episodes in Luxembourg not requiring prior authorisation and 138 with prior authorisation; Luxembourg was not able to provide data on reimbursements for care not requiring prior authorisation and reported 14 care reimbursements with prior authorisation.

Lower Austria/South Bohemia (Czechia)/Slovakia: Slovakia reimbursed a total of 5414 cases of care under the Directive in Czechia in 2019; Czechia reported 197 cases of reimbursement without PA in Austria and 130 in Slovakia. Austria reported no use of the Directive for care in Czechia or Slovakia and only 13 reimbursements in total under the Directive in 2019.

Poland/Czechia: Czechia made 916 reimbursements for planned care under the Directive in 2019, of which the majority (539) went to Germany, the remainder went to Austria and Slovakia, No reimbursements of care in Poland were reported. Poland reported 15,574 reimbursements of which 17,171 were for care in Czechia (note that the data reported above are for 2020 where COVID-19 reduced travel for planned care)

Study Objective 2: Available qualitative findings on the types of treatment for which patients seek cross-border healthcare:

Meuse Rhine:

Patients using the AOK/CZ cross-border card access all types of care. Patients from Germany also access primary care in the Netherlands.

Some clinical specialisations have established routine use of cross-border care. In some cases, this has been based on high demand and waiting lists in one country driving access to care in another, these care needs may be relatively short term.

Significant academic collaborations between the major teaching hospitals in the region drive awareness of the potential of cross-border care among healthcare professionals, in particular for rare-disease patients.

Language facility for patients who wish to access care in the language of the country over the border, which may be their first language.

Ease of use of a pre-authorised card system, over administrative complexity of the Directive and Regulations, the Regulation system is seen as too complex and the Directive system too costly for patients who will not get full reimbursement.

Grand Est (FR) Luxembourg:

A high number of border region workers use care in the two countries where they live and work, this is often funded under the designated cross-border worker mechanism in the regulations (PDA1).

Some disease areas are a particular focus of mobility, notably chemotherapy, which accounted for the highest proportion of publicly funded care in Luxembourg for French patients, followed by dialysis. For patients travelling from France to Germany, the most common care provided was for lymphoedema.

The fact that many doctors in Luxembourg have undertaken some or all of their training in France is reported to account for close professional relationships and referral for care in France, in particular in oncology and other complex diseases.

Well-developed relationships between hospitals established relationships between healthcare professionals often driven by training across several countries, rather than dedicated payment systems such as ZOAST operating between FR and BE.

Lower Austria/South Bohemia (Czechia)/Slovakia:

All types of care are accessed, but focal points exit around maternal and neonatal care, particularly in Gmünd and also between Hainburg (Austria) and the children's university hospital in Bratislava (Slovakia). Pregnancy and Birth was the single biggest care category in the data provided by the insurers, but the biggest patient group was from the United Arab Emirates.

A key influencer of cross-border care is local proximity to care, both specialist and routine.

The historical context of towns and cities which have in the past century changed national jurisdiction as new land borders were drawn. They create a mobility among the population based on shared history and territorial affinity which transcends borders.

Poland/Czechia:

NFZ received 940 requests for information in 2020, however, they reimbursed 6,513 patients, suggesting the NFZ is not a key source of information about cross-border care.

NFZ reported that of the 6,513 patients reimbursed nationally 5,514 patients obtained care in Czechia, and of those 2,736 live in the three provinces which border Czechia. Czechia is, therefore, the main choice for cross-border care in Poland, even for those not living in the border region. Of the 6,513 patients reimbursed in Poland,

4,838 were for cataract surgery.

Within Objective 2: Qualitative findings relating to the COVID-19 Pandemic and cross-border patient mobility

All case study regions experienced some disruption of normal patient mobility during the COVID-19 Pandemic, particularly in the first and second phases of the Pandemic, and due to border closures, which occurred as a result of public health restrictions. Border closures in some cases affected the normal operation of emergency services and cross-border patient transfers. Lack of systematic healthcare activity data sharing between countries led to difficulties in establishing rapid emergency responses to the need for urgent patient transfer and sharing of capacity in ICU facilities.

Cross-border worker mobility was also affected, and this had a particular impact on the healthcare workforce in border regions. Patient mobility under EU reimbursement mechanisms did, however, continue in some forms and these were used for the reimbursement of COVID-19 testing costs in some jurisdictions e.g., France. Further quantitative analysis will be required of validated data on use of the Directive and Regulations in the context of COVID-19 for the next reporting period and may shed further light on this issue.

In addition to the disruption of normal mobility arrangements as a result of the COVID-19 public health crisis, however, positive innovation also emerged- Euregio Meuse-Rhine, for example, took a lead role in coordinating a regional cross-border approach to the procurement of personal and protective equipment (PPE) for hospitals and related care settings in the region. In Luxembourg-Grand Est (FR) (within the framework of the Grande Region) high-level political agreements were developed at the height of the pandemic aimed at ensuring greater systematic cooperation in health, driven by the experience of the early COVID-19 Pandemic and the logistical challenges faced by acute and critical care services in hospitals. New collaborations are emerging between healthcare actors desiring to work more actively with regional cross-border stakeholders- Luxembourg is an example of this.

The Directive remains relevant as a reimbursement mechanism for planned care and there may be opportunities for regions to explore the role of the Directive in collaborative approaches to meeting the demand for planned/elective care- waiting lists for this have increased in all regions as a result of the COVID-19 Pandemic and its draw on overall healthcare system capacity and resources.

Study Objective 3: Methodological difficulties in monitoring patient flows and in collecting data on reimbursement mechanisms

While our study found easily accessible data in some countries with a national health insurer, such as Poland, there are additional challenges in collecting data where health insurance models are diversified between multiple providers. However, equally, some national insurers do not collect data which differentiates between the Directive and the Regulations.

In countries with a diversified health insurance economy, the challenges of fractured data collection processes can be overcome by the presence of insurers who are orientated towards serving the needs of border citizens and patients wishing to travel aboard. They have shown the potential to enhance the quality of data collected- in all case studies, we have identified a ‘coalition of the willing’- including insurers, who understand the specific challenges for citizens of accessing care in border regions and who have endeavoured to address these issues in a pro-active way.

Our study also identified examples of where umbrella organisations of insurers- such as the case of Austria- are willing to engage further on the issue of cross-border patient mobility data and who already provide a synthesis of existing data for the purposes of reporting to the European Commission.

Methodological difficulties discovered and articulated during the research process included varying interpretations of GDPR in relation to the collection of clinical data for statistical purposes and the degree to which this was perceived as possible.

Variations in the business processes underpinning cross-border patient mobility collaborations, and differences in the governance of these operations also present a factor in how easy or difficult data collection is- if data collection functions within organisations are not focused on or aligned to the cross-border aspect of care that an organisation may be involved in, then data collection becomes more difficult. The lack of interoperable health data systems also presents a standing challenge to the extraction of data for statistical and performance analysis purposes- however, through collaborative working and codesigned arrangements for sharing statistical data, more progress can be made. The absence of widespread interoperable patient data systems in border regions may be a challenge for the effective transmission of clinical information in the context of patient treatment, but it does not prevent other approaches to patient mobility monitoring and data sharing based on existing methods of data collection and supported by multistakeholder cooperation.

Overall, the extent to which it has been possible to systematically identify data that lies behind the NCP-reported figures on the directive is limited. This is because, beyond the requirement for Member States to report on patient mobility under the Directive and the Social Security Regulations, little consistency exists in how the data is collected which feeds into these figures. This is not a fault of any one institution in particular, rather the result of a diversity of purposes for which data may currently be collected. It also points to the opportunity- taking into account the overall issue of European Integration- for concerted work to address the gaps.

Data collection on patient mobility, where it happens, is done by individual agencies and organisations for their own internal purposes and the nature of this data is therefore determined by internal business requirements, rather than it being collected in the context of a wider, interagency agreed template and purpose for collection.

In general, the data discovery process has shown that the degree of possibility for more detailed data collection is influenced by the regulatory and legal relationship between the NCP/Ministries in Member States and health insurers. Our findings show that there is a willingness in border regions to be part of solutions for better data collection and codesigned data collaboration, partly due to the fact that in border regions there is a greater understanding of the relevance of such data – not only for supporting patient mobility but also in continuing to drive general healthcare cooperation and service planning in border regions.

Study Objective 4: Recommendations to improve data collection on patient mobility at EU-level for the purpose of Directive 2011/24/EU (reporting requirements under article 20) and actions which could be taken at regional, national and EU-level.

Detailed recommendations are contained in Section 4.4 of this report.

Recommendations draw on the relevance of regional and subnational stakeholders for the development of complementarity mechanisms for data collection which can support improved data collection for the purpose of the Directive. Recommendations also draw on the contribution which regional cross-border collaboration can have for this objective, and present suggested approaches to the establishment of data collection initiatives in border regions where there is existing capacity and political commitment to cross-border health cooperation in general. The recommendations highlight the importance of border regions as laboratories for EU integration, with much to offer their Member States and EU policy as a whole.

4.1.1 Comment on Overall Findings:

The case studies themselves depict a variety of contexts underlying the relatively high cross-border patient mobility rate in comparison to other EU countries which was the indicator used by the European Commission for their inclusion in this overall study. In this chapter, we have sought to bring together a set of observational findings and recommendations which take account of the differing conditions and priorities for cross-border patient mobility in the regions which formed the basis of the case studies.

The European Union has committed to the facilitation of access to cross-border healthcare through the adoption of the Cross-Border Healthcare Directive. For the EU to be able to plan services and implement this agenda in a meaningful and measurable way, this study has clearly shown that better data is required. It has also shown that there is a widespread understanding at the level of the case study regions of the benefits of good data collection and a willingness to get involved in helping to ensure citizens benefit from cross-border healthcare opportunities and good evidence-driven health service planning in general.

Some of the obstacles to better quality data require resolution at macro-level, such as the generalisation of knowledge, awareness, and operable models for streamlining the collection of statistical data on patient mobility within Member States and on borders in particular. A shared EU understanding of the benefits of digitalisation in generating better data for health and for planning, in general, is needed to underpin sustainable progress in cross-border care. This study raises issues which require both additional policy work and concerted actions to connect policy and practice at all levels of public governance.

Better health data, interoperability of digital health systems across borders, and a consensus on the relevance of these in the implementation of existing EU policy are all needed to release the full potential of existing mechanisms for cross-border patient mobility.

We have attempted, based on evidence gathered through the study, to illustrate some reasons for existing gaps in data and we have presented qualitative information which explains existing processes for data collection on patient mobility- and their limits in the absence of a whole-systems approach.

As with most literature published to date on patient mobility mechanisms, optimising the impact of these on the beneficiary target group (patients and citizens) depends

on understanding, navigating, and designing processes which address anomalies, prevent indirect discrimination for citizens- particularly those with disabilities, and facilitate efficiency in the delivery of health services. For this optimal impact to be levered, better data needs to inform the work.

There are strong imperatives to find ways of collecting better data to inform new approaches which can lead to a full expression of the rights of patients in cross-border health care. Specifically, it will be important to pay attention to the obstacles which may arise for patients with disabilities from differences in arrangements at national level concerning the need for reasonable accommodation of disability needs in terms of eligible costs for reimbursement, and pricing structures[93]. Only with good data can these issues be effectively addressed to the benefit of the patient.

A positive outlook on future approaches lies in the fact that the case studies have shown capacity for the necessary relationships and governance to be developed to address the issue of better data. If there is an agreed approach to a health data framework which facilitates aggregation of statistical data across borders, it will be easier for NCPs to gather data from insurers that is coordinated and consistent.

The role of centralised umbrella bodies for insurers- such as that in Austria- is a significant asset where insurance economies are diversified and involve multiple insurance providers (whether these are public, private or third sector-based). The role of insurers of healthcare with large client bases in border regions is also crucial, as while patient mobility itself may represent a small portion of their business, the sector of their client base that lives in a border region may be much greater. At national level, this is even more so. More than 30% of EU citizens live in a border region and the findings of this research may apply to all border-based health insurance market segments.

The presence in all case studies of an existing element of subsidiary collaborative working between national and subnational/regional actors (including insurers) is to be noted. This may not only represent capacity for further activation and mobilisation of the systems below the level of the Member States which can assist with better and deeper data on cross-border patient mobility but may allow for the development of agreed place-based approaches to developing shared statistical sets based on an agreed approach and template for data capture and collation relating to patient mobility. The case studies have identified in each case some evidence of interagency and intersectoral collaboration, focused variously on the issues of healthcare provision across borders, facilitation of patient mobility, and general health of border regions. These activities, importantly, involve civic leadership at regional level, as well as health care providers and insurers. These activities therefore already fit with the multisectoral model of 'place-based leadership' which underpins all existing good practice in the development of smart regions and cross-border regions. Border regions have an important and specific role to play in EU integration and are important domains for delivery of the priorities of the new Cohesion Policy.

What is missing from the landscape which the study has revealed is concerted

[93] See Appendix B- EDF analysis of NCP websites and national legislative provisions addressing the needs of people with disabilities.

systematic data collection on use of the Directive and other reimbursement mechanisms that reflects demographics, clinical needs and prevalence, and other indicators that can be useful as indicators of performance, service delivery and which can help with service improvement. AEBR has suggested a template that might assist with this process and this is contained in Appendix D to the study. Further work will be needed to establish a baseline template for data collection amongst interested parties in border regions.

Additionally, this study made it possible to identify some of the key stakeholders in the case study regions whose input would be relevant for future approaches to patient mobility data collection, development of a comprehensive regional schematic map of existing data collection and governance role lies beyond the scope of this study and is more appropriately linked to implementation of the Study recommendations. In this context, an important capacity-building action will be to develop a shared understanding among stakeholders in specific regions of the roles and responsibilities of all actors within the territorial ecosystem that supports cross-border patient mobility in those regions.

Understanding what kind of data needs to be collected in future is also important for an appreciation of what role the EU Health Data Space may have in contributing to a more data-driven culture across the EU healthcare and health services planning domain, and in particular how innovative solutions may be developed in the EHDS for export of anonymised statistical clinical activity and health data which can help inform service planning and patient mobility pathways- particularly in border regions. The three strands of focus for the EU Health Data Space (Clinical Data, Planning Data, and Data for Research) all have a particular relevance for border regions and how the EHDS addresses the matter of borders will be an important indicator of its success as an EU-wide initiative.

Currently, data collection on cross-border patient mobility under EU reimbursement mechanisms such as the Directive and the Regulations is derived ultimately from reimbursement cases and so far there is no obligation nor agreement with the Member States to extend this collection of information. This explains why there are gaps in information about the kinds of treatment sought- the key lies in the purpose for which data is collected.

There is an opportunity for the pilot initiatives recommended by this study to become test cases for the collection of more detailed data beyond the current set of indicators which relate purely to financial transactions on reimbursements. While such work is not dependent on progress on interoperability in the planned European Health Data Space, ultimately the regional and subnational data collection initiatives recommended can also demonstrate and catalyse the application of solutions from the European Health Data Space in a 'Lebenswelt' applied context.

As such, this study has identified collaborative health ecosystems in the regions which could represent a significant asset to their relevant Member States in addressing both the opportunities and challenges of health, healthcare, and patient mobility in border regions. These regional health ecosystems also represent a framework to reinforce the aspects of the Directive which deal with border regions.

Collaboration on patient mobility data, as set out in the recommendations, should take account of the following issues arising from our findings:

- Agreed data sets for cross-border patient mobility based on the AEBR data capture template as a starting point; this kind of data is relevant for all patient groups, many of whom are vulnerable and in pain (cancer, chronic orthopaedic conditions, etc.)
- Identification of issues associated with the resourcing, planning and delivery of healthcare and population health planning/interventions which cannot be solved unless clinical healthcare performance statistics can be integrated into regional data sets;
- Interaction with those driving the European Health Data Space on the data requirements for better cross-border patient mobility and to ensure that the expertise and learning from the collaborative working (partnerships) in the case study region can influence future frameworks and solutions emerging from the EU Health Data Space.

In general, our findings indicate that the view of stakeholders on possibilities for future data collection is that for it to work best, there must be a reason and purpose for data. There are good reasons to collect better data, not least in the case of ensuring that implementation of cross-border patient mobility reimbursement arrangements do not impinge upon or act as barriers to patients across the EU. What generally underlie gaps in data are gaps in working relationships and governance of systems which facilitate access to cross-border care for patients. To work effectively on data collection and the use of that data, such systems must involve both national and regional players. Multilevel, multistakeholder partnerships working on agreed shared priorities that patient flow is necessary information for healthcare systems planning and with appropriate business processes underpinning that work are important conditions for quality data.

Our findings further reinforce the sense that good data collection on shared, agreed templates, will occur where there is a purpose for that data. The 'purpose' may be further work at different levels of governance within Member States, for example between regional players such as civic border regional structures in coalition with healthcare providers, insurers, and advocacy organisations. The collection of data requires streamlining with internal operational and business processes and requires resourcing through workforce planning. The importance of a shared interagency data collection objective which is fully endorsed by partners (individual organisations) is that this then determines the weight which is given by an individual organisation to the matter of data collection. In this sense, it is impossible to make recommendations for future approaches to data collection without considering the purposes which might be supported by that data, and the evidence-informed opportunities which might be released by a shared and committed multistakeholder approach to joint working supported by collaborative evidence.

4.2 Conclusions and Recommendations

This section sets out the conclusions and recommendations of the study together, aligned with the research objectives, and identifies stakeholders who should be involved in implementation of the recommendations. The study makes 9 recommendations in total, across the full range of research objectives and on a number of related sub-themes.

Research objectives and relevant subthemes:	**Conclusions**	**Recommendations (9 in total)**	**Who needs to be involved**
1. **Collection of available data on patient mobility and different reimbursement mechanisms (Regulation on social security coordination mechanisms and the Directive on patients' rights in cross-border healthcare);** 2. **Gathering of qualitative information, where available and feasible, on the types of treatment for which patients seek cross-border healthcare or information on patient mobility within the**	Article 20 of the Directive sets a legal requirement for Member States to report available data which enables monitoring of the Directive on the rights of patients in cross-border healthcare; the findings from this study (which has also involved a review of existing data reported to the Commission) suggest that the totality of data collected by insurers and regional bodies is not always reflected in the reports made annually to the European Commission by Member State NCPs. Despite extended data source mapping and discovery undertaken during this study, findings indicate that the overall state of both quantitative and qualitative data collection on EU cross-border patient mobility lacks consistency and is piecemeal; it is largely dependent on in-country arrangements for data collection and sharing- these vary across Member States.	1. Member States should work with health insurers and all other relevant data owners (including healthcare providers and cross-border organisations) to develop in-country mechanisms to ensure that better data is available and reported to the European Commission on cross-border patient mobility as required by the Directive on patients' rights in cross-border healthcare, as follows: Data collection mechanisms should be improved to ensure that data collected on cross-border care includes information on types of treatment accessed, and can differentiate between different reimbursement tools used, including local and regional tools. The data collection tools should be expanded to include demographic data on patients as well as categories of care accessed (ideally by clinical classification) to allow for fuller assessments of use and needs to be made.	NCPs; Health ministries; Regional cross border organisations; Subnational and regional organisations involved in facilitating cross border healthcare; National and regional statistical offices; Health insurers; Patient representatives.

context of COVID-19 (COVID-19 and non-COVID-19 patients) and of communication on cohesion in border regions;	Some Member States do not report any data to the European Commission on cross border patient mobility. Solutions and opportunities for innovation in cross-border patient mobility cannot be determined in an environment where there is no data evidence to work from. Currently reported data are often purely financial in nature and are largely derived from insurers. While the Directive does not require the collection of qualitative data on types of care accessed, collection of this data should be considered in the context of future data collection and reporting. [94] Data gaps can, however, be addressed through appropriate collaborative governance for data sharing and collection between healthcare providers and insurers on the understanding that a more complete picture of patient mobility is a desirable outcome with multiple potential benefits for Member States and border region populations. The case studies have identified that there is capacity at the subnational and regional cross-border level for these shared approaches to data collection involving multilevel stakeholders	Such mechanisms should be developed on a multilevel basis with a range of partners in cross-border regions, allowing neighbouring NCPs to coordinate and reduce duplication of effort and resources.	

[94] A best practice example of where financial reimbursement data and clinical activity data are combined in reports on cross-border patient mobility are the data reported by Ireland/Northern Ireland prior to 2019, contained within: Data report on the application of the Directive in EU countries (2019)https://ec.europa.eu/health/cross_border_care/overview_en

	and appropriate governance. The COVID-19 Pandemic highlighted the importance of good quality data in the effective functioning of healthcare systems both domestically and across borders (where urgent patient transfers were concerned). It is important to ensure that the European Union has well-functioning and effective healthcare systems. A core feature of these must be good data on population health needs, healthcare demand, and healthcare activity which allows for the monitoring and improvement of healthcare systems. While data on cross-border patient mobility is a small subset of overall healthcare data, it underpins an important legal commitment of all Member States and the EU to supporting patient rights in cross-border healthcare for all patients.		
3. Understanding the methodological difficulties associated with data collection on patient mobility: integrating various data collection streams to provide better information on cross-	Any gaps in data or methodological difficulties are the result of a fractured approach to data collection involving different stakeholders operating independently of each other and without shared approaches to data collection. Data capture design and collection needs to be based on best practice approaches to data collection and co-designed collaborative	2. Member States should be encouraged to establish pilot collaborative data design and collection initiatives in border regions including those covered in the case studies. Pilot initiatives could be resourced with the assistance of the European Commission and should include the following terms of reference: A) Mapping and testing regional/sectoral	DG SANTE; DG REGIO; Euregio structures/regional cross border cooperation organisations with a track record in health cooperation;

border patient mobility.	governance for data sharing; it needs to be a collaborative process involving Member States' NCPs and relevant stakeholders in healthcare provision, healthcare insurance, and in regional cross-border collaboration[95]. A useful vehicle for new approaches to data collection lies in the evidenced capacity and presence of relevant stakeholders in the case study regions of this study and the potential for place-based pilots[96] to develop workable best practice and generate learning for replication. Border regions are recognised by the European Commission as important laboratories for European Integration and as such may provide a useful template for co-designing, testing, and implementing improved approaches to cross-border patient mobility data. They are also key	capabilities for providing more detailed data on patient mobility for the reporting period covering 2021-23; B) Co-designing schematic approaches to future data collection on patient mobility which include specific data on the use of the Regulation, the Directive, and other reimbursement mechanisms; using an action research[97] approach where relevant; C) Exploring how additional cooperation on patient mobility data can support the planning of future collaborative approaches on cross-border healthcare that are aligned with population health needs (including key population health risks documented for Member States in the EU's Country Health profiles /Health at A Glance reports)[98]. Quantitative data could be complemented by data drawn from patient journey mapping (a healthcare service	ERNs; NCPs; Health ministries and Regional cross-border organisations; Subnational and regional organisations involved in facilitating cross border healthcare; National and regional statistical offices; Health insurers; Patient representatives; Interreg Programme and related

[95] 'Law and policy from non-health sectors is as important for EU health governance as the body of law and policy that explicitly targets health'. Eleanor Brooks & Mary Guy: EU health law and policy: shaping a future research agenda in *Journal of Health Economics, Policy and Law (2021), 16, 1–7 doi:10.1017/S1744133120000274;* last accessed on 17/11/2021; p5.

[96] Drawing on existing work by initiatives such as EUPrevent in Meuse Rhein; also developing the concept of the Health Data Observatory proposed for Grand Est (France)- see case studies 1 and 3.

[97] Action research has been in use by healthcare systems at the macro and micro level since the 1990s, as a way of ensuring system and service improvement is evidence-based and in particular that a methodical approach is taken to introducing or designing changes in operations at different levels of a system. It has informed a wide range of service and clinical care quality improvement methodologies, is also at the heart of LEAN and SMART system improvement tools. Background on the technique can be found in Ralph Nichols (1997/2006)) Action research in health care: the collaborative action research network health cahttps://doi.org/10.1080/09650799700200032; last accessed on 17/11/2021

[98] Health at a Glance: Europe | Public Health (europa.eu)

	drivers of data-driven territorial cooperation and spatial planning. Civic organisations in border regions are useful partners for Member States and health sector stakeholders in addressing the challenges of cross-border patient mobility data and are experienced in facilitating the kind of collaborative approach that this study recommends.	improvement methodology which is well established internationally)[99]; D) Exploring with regional actors how integration of health and patient mobility data with regional spatial planning evidence bases and action research processes (e.g., Smart Regions, Smart Cities, ESPON network projects) can lever added benefits for future data collection on patient mobility. Regions should also consider how European Digital Innovation Hubs[100] can support more effective use of digital health tools to support patient mobility and mobility of care expertise to support resilient regions. For example, this could include exploration of the European Reference Network model to address areas of clinical need outside the rare diseases category.	initiatives.
Subtheme: **Data Collection – a connected approach**	The creation of the European Health Data Space (EHDS), and the development of interoperable healthcare data systems across the EU may have a role to play in facilitating better statistical data on cross-border patient mobility which goes beyond financial transaction/reimbursement data. Digital medical and health records and wider digital health data systems are being rolled out in some form in all EU Member States; their potential to feed the EHDS with	3. The development of the EU Health Data Space should include exploration of how interoperability of patient data systems can also support the collection of statistical data on cross-border patient mobility.	European Commission; EHDS Actors; Data Collaboratives in key border regions comprising key territorial partners who responded to the study; Healthcare

[99] Trebble/Hansi/ Hydes/Smith/Baker: *Process mapping the patient journey- an Introduction* in *BMJ* 2010; 341 DOI: https://doi.org/10.1136/bmj.c4078 (2010); last accessed 29/11/2021.

	statistical data relevant for wider healthcare system planning should be fully explored.		organisations in border regions; Cross-border territorial cooperation organisations in border regions; Spatial Planning stakeholders in border regions; Health and demographics data experts; Healthcare insurers; EUROSTAT; ESPON.
Subtheme: **Improving the qualitative conditions for cross border patient mobility**	The Directive and Social Security Regulations are a legal framework for the operation of reimbursements of the costs of cross-border care across the EU. They are tools which can be used to optimal effect when actors at Member State and subnational/regional (and regional cross-border) levels create the conditions on the ground for effective healthcare cooperation. The case studies have shown that there is both the will and the potential in border regions for opportunities to exploring complementarity and cooperation in healthcare on borders, which make can best use of resources in a way which benefits cross-border territories and wider health economies of Member States. While the Directive does not require	4. Technical support and resources should be provided for key border regions including the case study regions, to explore options and facilitate solutions for more structural regional cross-border healthcare cooperations which are based on complementarity, critical mass, and cross-border patient catchment populations. These should include: a) the joint-commissioning of high-cost clinical capital equipment; b) shared approaches to specialty services and hospital collaboration in border areas; and c) development of advocacy actions focused on the role of functional cross-border health regions in contributing to national excellence and improvement in healthcare.	European Commission; Member State Health Ministries (or/and their regional arm where this is relevant); Clusters of hospitals and healthcare providers in border regions; Border region healthcare organisations (including clinical leaders); Civic authorities in

	specific reporting on patient mobility in border regions, border regions are often the places where innovative and highly efficient sharing of resources is already happening and can be further developed. These may present good practice for wider healthcare systems while also meeting the specific needs of border populations- the latter are acknowledged in the legislation as a specific beneficiary group for the Directive.		border regions including cross-border bodies and Euregio structures.
Subtheme: **Improving the qualitative conditions for cross border patient mobility– greater cooperation on clinical care and clinical innovation for cross-border patient populations.**	This study has shown that there are specific and common population health needs amongst cross-border patient catchments in border regions which can be met through clinical and institutional collaboration between healthcare providers and insurers in border regions. Cross-border regions often have common population health needs and there is a desire for greater clinical collaboration across borders in many border regions. Specific support to clinical leaders in developing clinical care networks which are cross- border, have particular benefits to border communities who are often distanced from centres of clinical excellence within their Member States. The ultimate outcome of this can be to improve population health, address health inequalities, and contribute to an international body of clinical evidence, knowledge, and practice. Good data underpins effective planning for population health and service planning.	5. Further exploration of approaches to clinical care provision which are based on evidence of population health needs in border areas (as a basis for coordinated shared services and also clinical innovation in patient care including the development of integrated care models).	Clinical specialists based in hospitals or primary care settings close to borders; Hospitals and primary care providers close to borders; Regional cross-border organisations Public health agencies.

Subtheme: **Improving the qualitative conditions for cross border patient mobility –improved approaches to patient awareness, quality of information for patients, and improving access to information on healthcare abroad**	More can be done in all case study regions to improve patient awareness and information on cross-border patient mobility options. NCPs can explore partnership opportunities with regional and subnational organisations in the case study regions to provide patient information in a way that is targeted to populations and demand on the ground. This study has shown examples of good practice in regional-level action to improve patient information.	6. NCPs should liaise with stakeholders in border regions to determine if there may be collaborative approaches to: c) Improving awareness and availability of information to all patients through a variety of approaches and outreach at local level as well as information on NCP websites; d) Within this, improving access to information for patients with disabilities (drawing on the report provided by the European Disability Forum for the purposes of this study, and other relevant evidence on the Directive and patients with disabilities).[101] e) Improving access to information for patients with rare diseases and their families/carers.	National Contact Points; Healthcare Providers; Insurers Disability Rights and Patient Advocacy organisations (national and EU-Wide); Regional healthcare providers; Civic authorities providing citizens' information; Patient Advocacy organisations.
Subtheme: **Improving the qualitative conditions for cross border patient mobility- creating good quality baseline information that can be used to inform**	In regions where socio-economic discrepancies across borders are more acute, and where pricing structures are not known or understood by patients and providers, this baseline information is essential to support patients' access to their rights in cross-	7. Where baseline information does not exist for patients who want to access cross-border care, and where there may be cross-border socio-economic discrepancies between Member State of residence and Member State in which care is being sought, the European Commission and the	European Commission; Research institutions/health economists; Hospitals and other

[101] In keeping with the spirit of the Charter of Fundamental Rights of the EU (Articles 21 and 26), EU data collection on cross-border healthcare should include the good practice of gathering data which supports a better understanding of how to support the rights of patients with disabilities in the context of cross border healthcare.

patients and providers about options	border healthcare.	wider EU community of research institutions and programmes should explore ways to support baseline work to create patient information (e.g., pricing structures) and capacity building in key border regions.	healthcare providers in border regions; Insurers.
Subtheme: **Impact of COVID-19 Pandemic on cross border patient mobility**	Further analysis will be required of the validated data for the current reporting period to determine the full impact of the COVID-19 Pandemic on cross-border patient mobility. However, qualitative findings indicate that COVID-19 responses disrupted both unscheduled and planned cross-border care. In some cases, border closures impacted both patient and healthcare workforce mobility. The COVID-19 Pandemic has also led to a planned and elective care crisis across Europe with long waiting lists. The implications of this for the health of EU citizens and for the EU economy are significant. The Directive is an EU-wide reimbursement mechanism specifically aimed at supporting planned care and while it was introduced pre-pandemic, it may be an important and durable asset in the EU and its Member States' responses to post-COVID-19 recovery and resilience. Member States may wish to consider whether the Directive may have a role in alleviating the pressures faced by all Member States' healthcare systems through facilitating	8. Using innovative cross-border collaboration between neighbouring countries and in border regions, Member States should: c) Explore the role of the Directive in addressing the demand for planned care throughout the EU, and in border regions, arising from the COVID-19 Pandemic; and d) Develop shared protocols between Member States for cross-border patient mobility and frontier worker mobility based on learning from the COVID-19 pandemic and in interests of keeping patient pathways open and guaranteeing the healthcare workforce mobility required for health services to operate to their full capacity with safe levels of staffing.	Healthcare providers in border regions; Insurers; Regional and local authorities in border regions; Regional and national civic authorities.

	mutual cooperation on planned care with the input of subnational and regional healthcare actors- particularly in border regions where proximity and access are interlinked.		
Main recommendation linked to overall study outcomes	This study has shown that there may be benefit in promoting an EU-wide institutional awareness at EU, national and regional levels of future opportunities for cross-border cooperation to deliver on patient rights and social protection rights in border regions, using a) existing EU mechanisms such as the Directive and the Social Security Regulations and b) mobilising and supporting capacity in border regions for more intensive structural innovation through collaborative working.	9. Follow up and take forward the findings of this study with key actors within the European Commission and Member States	European Commission; Stakeholders in the field of cross-border cooperation and health; Stakeholders in the field of EU regional and cross-border policy.

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