IDERHA Task 6.3 Patient workshop 14/09/2023- Executive summary

The IDERHA project's inaugural multi-stakeholder workshop held on September 14, 2023, gathered nine participants from the public representing IDERHA's patient organisation partners, European Cancer Patient Coalition (ECPC), Lung Cancer Europe (LuCE), European Patients' Forum (EPF). These participants, from across Europe, including France, Greece, the Netherlands, Romania, Slovakia, Spain, Turkey, and the UK, had varied backgrounds and experiences, with some directly affected by cancer. The workshop provided valuable insights into participants' understanding of health data, concerns about data fragmentation, and their willingness to share health data. It highlighted the significance of patient data privacy, security, and data literacy, and the need for clear communication. The workshop laid the foundation for future discussions on topics such as data quality, AI tools, and consent, ensuring a collaborative approach within the IDERHA project. This is the first of several workshops seeking patient engagement and is part of the project's commitment to incorporating the patient perspective in developing policy recommendations related to health data access and sharing.

Conclusion

The IDERHA patient workshop revealed valuable insights into participants' perspectives on the project and health data in general. It highlighted the diverse nature of health data, emphasising its significance for individuals dealing with rare diseases and the need for comprehensive, yet understandable communication about data collection and consent. The participants' concerns revolved around data fragmentation, security, and the legislative framework to protect patient rights and privacy. They recognised the potential benefits of the IDERHA project but stressed the importance of privacy, trust, and data literacy in ensuring its success. This workshop provided a platform for patients to voice their views and identified key areas, such as data quality, AI tools, and consent, for future discussions and collaboration.

Key recommendations and priority areas

The following recommendations could address key concerns raised by workshop participants and should be considered within the IDERHA project:

1. Strengthen data privacy and security measures: Prioritise robust data security measures to protect patients' rights and privacy. This includes implementing legislative frameworks to govern health data access, sharing, and consent. Building trust among individuals and communities is crucial for ensuring public and patient willingness to share their health data.
2. Improve data literacy and communication: Recognise the importance of clear and plain language communication to enhance data literacy among the general public. Raising awareness about the benefits of sharing health data and dispelling

misconceptions about data collection can foster greater public support for data sharing initiatives.

IDERHA Task 6.3 Patient workshop 14/09/2023- Full report

Introduction

The IDERHA project launched its multi-stakeholder workshop series on 14 September 2023, aimed at supporting its work on developing consensus on policy recommendations concerning the access, sharing, and integration of health data.

The inaugural workshop brought together nine members of the public who belong to three of IDERHA's patient organisation partners, the European Cancer Patient Coalition, Lung Cancer Europe, and the European Patients' Forum. Representatives from France, Greece, the Netherlands, Romania, Slovakia, Spain, Turkey, and the UK attended the workshop. The patient representatives had diverse backgrounds, and many had personal experience with cancer or had close family members who had been affected by the disease.

The decision for the first workshop to be patient focused, reflects the importance of patient input within IDERHA. Patient voice will play a major role in the development of consensus on policy recommendations regarding ethical and legal governance of heterogeneous health data access and sharing. The patient participants all rated themselves as having an average or significant understanding of how health data is currently used. In addition, 13 IDERHA members were in attendance.

During the workshop, participants received an introduction to the IDERHA project, gaining insights into how the project aims to change how health data can be used in the future for patient and research benefit. Workshop participants were encouraged to discuss their opinions on IDERHA's objectives and express any potential concerns they may have.

What is health data?

To begin discussion, participants were asked to share their perspectives on what health data meant to them. Participant comments included:

- Health data encompasses patient information covering various aspects, such as vital metrics like blood pressure and a patient's treatment history, both current and past. It was emphasised that for individuals dealing with rare diseases or specific conditions, sharing health data was critical for understanding what treatments worked and what didn't, leading to potential adjustments in their treatment plans.

- Health data refers to any information related to an individual's health, creating a unique and personal connection to that person.

- The broad spectrum of health data was discussed, including data collected from individuals for example collected by healthcare professionals. The importance of considering information about the health of a group or population of people was highlighted e.g., types of mutations, and data sources such as biobanks.

- Confidentiality in health data was also discussed. It was suggested that patients may be hesitant to share their personal data with others. This raised the sensitive issue of how far one's personal health data should be shared with external parties, particularly for research or healthcare purposes for example, people might be more reluctant when commercial organisations use their data.

Understanding of how health data is used

Participants were asked in a poll to rate their own perceived level of understanding of how their health data is currently used, with the following options: no understanding, little, average, good or significant understanding. All participants rated themselves as having an average or significant understanding of how health data is currently used, reflecting a relatively informed group of individuals.

It was highlighted that this group of empowered patients might have a greater level of understanding than the general population. It was also noted that while they have a good understanding of what health data is, they have limited knowledge about how it is being used. This nuanced view pointed out the importance of distinguishing between understanding what data is and comprehending its actual usage.

Concerns about data fragmentation and data sharing

Participants were asked how concerned they were about the current fragmentation of health data, they were asked to score from 1 to 10, where 1 was not at all concerned and 10 was extremely concerned. The responses varied, reflecting diverse viewpoints within the group (Figure 1).

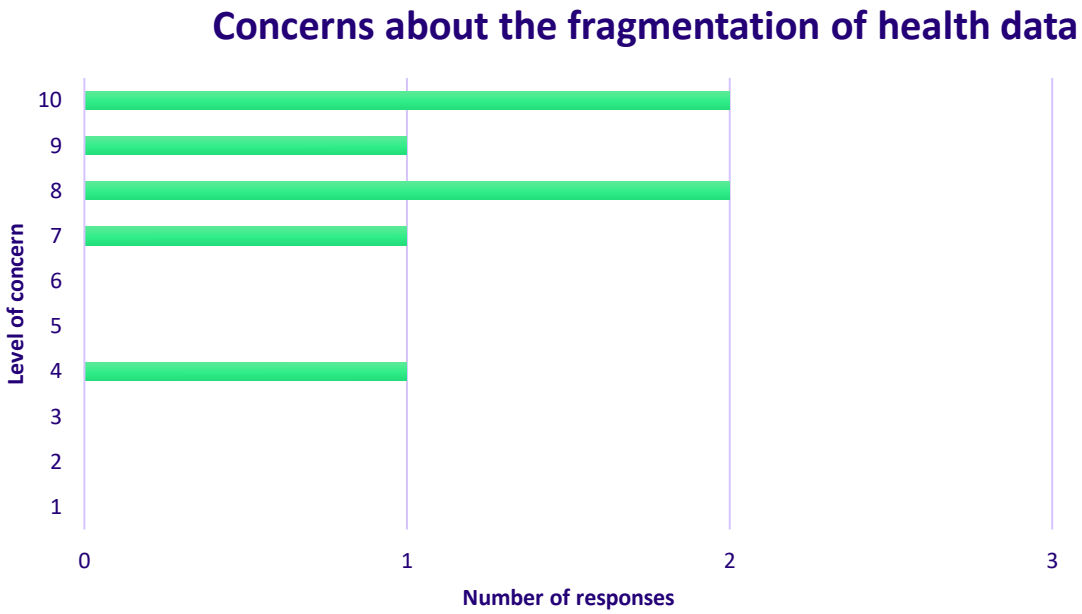

Figure 1. Participant concerns about the fragmentation of health data (1 – Not at all concerned, 10 - Extremely concerned)

Participant comments regarding their level of concern about the fragmentation of health data included:

- A participant who scored "10", indicating extreme concern, pointed out the importance of breaking down data silos, especially concerning compassionate use programs, as fragmented data could lead to critical information not being shared between healthcare providers (doctors and pharmacists).

- A "9" score highlighted the difficulties they faced as a patient who used two different international healthcare systems. These systems were not interoperable, requiring manual translation of documents and data sharing between different healthcare providers. They also flagged the importance of sharing data for rare diseases where few people have the condition.

- An "8" score reported their experiences when they were a patient and how they had to manage data from different healthcare entities, such as labs, pharmacies, and hospitals, which were not connected. This experience was challenging, and they emphasised the need for better data exchange and integration, particularly to relieve patients of the burden of managing their own data. They were able to manage it but could imagine that this is not possible for everyone and that this would cause many losses.

- A "7" explained that on the one hand, data privacy is important, but on the other hand, if there is no integration of the data, it is almost impossible to diagnose people

in early stages of the disease especially for diseases that require early detection to save lives. They brought up the term “silent killer”.

- One individual who scored a “4” expressed an understanding of the fragmentation issue but noted that their personal level of concern was low. They suggested that the benefits of data integration might outweigh concerns.

- Another participant described themselves as not being concerned that the data is fragmented, but more concerned about the reuse of the data. They noted that there is a need for a legislative framework before trying to find methods to put these data together. It would be important to ensure that the patient’s rights and privacy are protected.

Reservations about sharing health data

Participants were asked how much they agree or disagree with the following poll question “I have reservations about sharing my health data”. Scoring on a scale of 1-10, where 1 is completely disagree and 10 is completely agree. All participants scored a 5 or lower, suggesting that this particular group were not as concerned about sharing their health data (Figure 2).

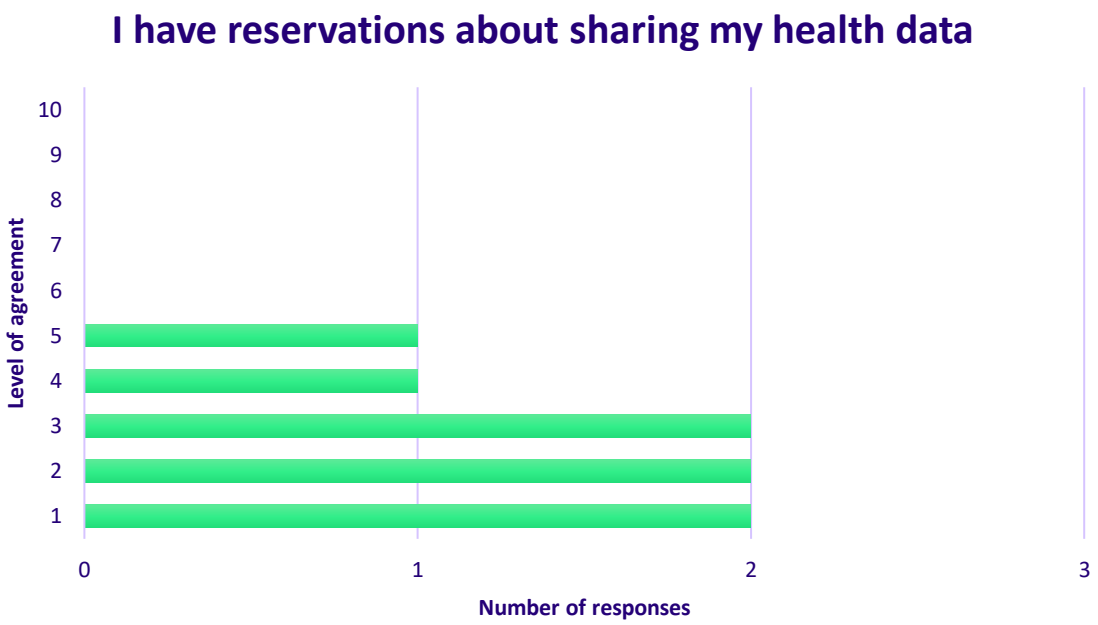

Figure 2. Do participants agree or disagree with the statement ‘I have reservations about sharing my health data’ (1 – Completely disagree, 10 - Completely agree)

Participant comments included:

- There is a need for clarification regarding sharing health data with medical professionals, compared to sharing with others outside the healthcare system. They indicated a willingness to share data with healthcare providers but emphasised the importance of a legislative framework when sharing data with non-medical entities. They also emphasised the importance of protecting patients' rights when sharing health data.

- One's willingness to share health data may depend on various factors, including cultural and age-related aspects. They explained that older people may be more willing to share their data, as opposed to younger people. They also explained that if the data was aggregated, there may be more willingness to share their data, than if it was identifiable.

- The security of data is an issue, thus highlighting the need to ensure data security and prevent unauthorised access, especially in the context of hackers potentially targeting health data.

IDERHA project details

In this section of the workshop, Lena Hegel discussed the practical aspects of the IDERHA project, and its benefits. The themes discussed included, data sources, federated data infrastructure, data security, data integration, AI algorithms, clinical decision support, and individual benefit. Workshop participants were given the opportunity to comment on this. Comments included:

- Concerns about the lack of data standardisation in health records. In response, it was described that there is a work package dedicated to data standardisation and the use of the OMOP common data model to achieve this.

- Possibility of diagnosis depends on the country and resources of the health care system. Hence, the data quality and completeness of the data would depend very much on the country and the conclusions drawn from these data could be biased.

- There was a question about how the project plans to provide patients with access to their data, especially regarding sensitive information like cancer prognosis. It was clarified that the application primarily helps patients organise and give consent for their data but doesn't directly communicate sensitive prognostic information.

- There were concerns about patient attitudes toward testing and data uptake, as well as the challenges of clinicians identifying relationships between symptoms and conditions.

Opinions and key concerns from patients' perspectives on the IDERHA project

In this part of the workshop, the discussion centred around the participants sharing their thoughts and concerns regarding the project. The following themes were identified:

- Positive Feedback: Participants expressed overall support for the IDERHA project, recognising its importance and necessity in the field of precision medicine. They highlighted the need to break down data silos, integrate different types of health data, and make data more accessible for research and decision-making.

- Concerns on Communication: Concerns were raised regarding effective communication, especially with patients and the general public. Participants stressed the need for clear and plain language communication to ensure that all stakeholders, including patients, can understand the project's goals and processes. Proper communication about data collection and consent was emphasised.

- Importance of Data Literacy: It was noted that improving health literacy and media literacy is vital. The general public needs to understand how sharing data can benefit them and that not all data collection is harmful. Raising awareness and understanding the value of data sharing is crucial.

- Security and Trust: Security and trust were highlighted as significant challenges. Participants emphasised the need for strong data security measures and trust-building mechanisms to ensure public and patient willingness to share data. Participants also discussed the challenges in getting the public to agree to data sharing and how to maintain the relationship of trust with individuals and communities.

- Data Privacy: Privacy and ensuring individuals have control over their data were key concerns. The project needs to guarantee data privacy and provide transparency in data handling and consent processes.

- Data Accessibility and Usefulness: Another concern was ensuring that the data collected is made accessible, and that it is useful for improving healthcare and research. Generally, perceptions were positive.

Feedback on the benefits and concerns of the project

In this section, the benefits of the project were explained. The benefits were categorised into three main areas: research, healthcare organisations, and individuals. The integration of data would allow faster and cheaper research using high quality data. This would allow to improve patient’s outcomes. The patients will be able to decide which data they share for which purposes. This discussion underscored the significance of privacy, consent, and legal support

in ensuring the success and acceptance of the IDERHA project. The discussion included the following patient input:

- The necessity of an EU resolution for the establishment of a European legislative framework to support patients' consent and data security was highlighted, stressing that patients wouldn't provide consent without these protections.

- People generally don't have issues with sharing data but there was an emphasis on the responsibility of handling data correctly. They also referred to upcoming European legislation and the need to raise awareness about data privacy and protection.

Topics for future workshops

The workshop concluded with a final poll discussing which topics could be the focus for further patient workshops. Participants were given the following 5 options: data quality and linkage; new AI tools; consent; secondary use of data for evidence in developing and assessing medicines; anonymisation/pseudonymisation. All topics received at least one vote, indicating an appetite for more workshops. Other suggested topics included what data patient participants would like to see collected across Europe, and data collection.

Conclusion

The IDERHA patient workshop revealed valuable insights into participants' perspectives on the project and health data in general. It highlighted the diverse nature of health data, emphasising its significance for individuals dealing with rare diseases and the need for comprehensive, yet understandable communication about data collection and consent. The participants' concerns revolved around data fragmentation, security, and the legislative framework to protect patient rights and privacy. They recognised the potential benefits of the IDERHA project but stressed the importance of privacy, trust, and data literacy in ensuring its success. This workshop provided a platform for patients to voice their views and identified key areas, such as data quality, AI tools, and consent, for future discussions and collaboration.

Appendix

Attendees

The patient workshop consisted of 9 participants representing various IDERHA patient organisations, including the European Cancer Patient Coalition (ECPC), European Patients' Forum (EPF), and Lung Cancer Europe (LuCE). The participants had diverse experiences, with individuals either having personal experience with cancer, or having family members affected by cancer. The participants were from a wide range of European countries, including Spain, the UK, France, Romania, Slovakia, Turkey, Greece, and the Netherlands, providing a wide range of perspectives and insights.

There were 13 IDERHA members in attendance including:

Name	**Organisation**
Alfonso Aguarón	Lung Cancer Europe
Ravinder Claire*	National Institute for Health and Care Excellence
Heather Colvin	Johnson & Johnson
Katharine Cresswell*	National Institute for Health and Care Excellence
Dominik Geller	Hygiaso
Lena Hegel*	Fraunhofer-Gesellschaft
George Kolostoumpis	European Cancer Patient Coalition
Rebecca Lumsden*	Sanofi
Kathrin Morasek	Ludwig Boltzmann Institut/Medizinische Universitaet Wien
Simon Scheider*	Fraunhofer-Gesellschaft
Tanja Stamm	Medizinische Universitaet Wien
Gözde Susuzlu	European Patients' Forum
Morten Deleuran Terkildsen	DEFACTUM

*Speaker

Workshop agenda

Agenda item	**Speaker/Moderator**
Introductions and welcome	Ravinder Claire
Overview of IDERHA	Ravinder Claire
Problems around data sharing and linkage	Rebecca Lumsden
How IDERHA is tackling these problems	Lena Hegel/Simon Scheider
Benefits of IIDERHA	Katharine Cresswell
Discussion	Katharine Cresswell