Personalised healthcare playbook for health advocates

Your guide to education and action towards personalised healthcare

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Foreword

Personalised healthcare is more than just a buzzword of the moment.

It is an approach that has the potential to **radically improve outcomes for people affected by health conditions and their communities**, whilst benefiting **healthcare systems and societies** around the world.

People affected by health conditions, healthcare practitioners, regulators, policy makers and the population at large are still discovering the potential **paradigm shift** that personalised healthcare represents, and with new areas continuously emerging, personalised healthcare interventions are already **pushing beyond the limits** of some healthcare ecosystems.

As the landscape of healthcare shifts and evolves, never has it been more important to **understand, educate and advocate for personalised healthcare**, with the aim of improving individual outcomes and achieving effective and sustainable healthcare for all within the community.

"Personalised healthcare involves the tailoring of care to an individual's unique health needs and preferences"

Continuous glucose monitoring technology helps people living with diabetes to self-manage the condition[2]

Progress in non-small cell lung cancer and biomarker research has lead to a dramatic shift in how lung cancer is treated[3]

Contents

About this playbook

This playbook is intended to help health advocates and people affected by health conditions identify action areas under the following core topics to improve understanding of, and access to, personalised healthcare options for your community:

Personalised Healthcare Literacy Building & Empowerment	**Ecosystem Development & Policy**	**Data & Digitalisation of Healthcare**

It is designed as a resource you can personalise to your needs for building literacy, supporting education and engaging in advocacy in personalised healthcare.

The playbook is a living repository of best practice examples, guidance and tools, through which health advocates can navigate, identifying the topics or action areas they feel are most important. Most examples and resources included are not specific to one health condition, however some condition-specific examples have been included as best practice case studies and will be expanded over time.

Navigation tips

Jump to contents page

Jump to topic overview page

Jump to previous or next action area

Go back to the first page of the topic in focus

Learn how to use and navigate the playbook

How does this playbook work?

Choose a topic	Identify action area	Review and utilise resources

- If you are new to the playbook, read **pages 7 and 8** for background on the topics
- On page 9 you will see **three topics** displayed, **within which health advocates can take action** for personalised healthcare
- **Choose a topic to begin**

- **Use the 'Read more about…' descriptions** and choose the one that best **describes your current need or interest**
- For each description, there are 1-4 example implementation activities that you can carry out

- **Click on each implementation activity** to reveal guidance and tools, and best practice examples you can use to improve understanding of, and access to, personalised healthcare options for that topic
- Click on the links to access supporting **tools and resources**

Personalised healthcare is constantly evolving with a growing community benefitting from, engaging in and advocating towards it

There are 50 unique elements* needed to achieve personalised healthcare across different countries and health systems, as identified by a panel of experts. These elements form 17 Building Blocks, which span four core categories:

***Find out more** about how these elements were identified at the FutureProofing healthcare website. It includes analysis of >80 healthcare plans, interviews and validation by industry, healthcare practitioners and health advocates.*

PLANNING AND ENABLERS

1 STRATEGY AND INVESTMENT
VISION • LEADERSHIP • FUNDING
IMPLEMENTATION STRATEGY
COMMUNICATION

2 PATIENT AWARENESS AND EMPOWERMENT
HEALTH LITERACY
EDUCATION AND SKILLS ON PERSONALISED HEALTHCARE

3 WORKFORCE
PERSONALISED HEALTHCARE AWARENESS
EDUCATION AND SKILLS ON PERSONALISED HEALTHCARE
CAPACITY PLANNING

4 COLLABORATION
KNOWLEDGE NETWORKS • INNOVATION HUBS
MULTI-PARTY BIDDING FOR HEALTH SERVICES
HEALTH SYSTEMS PARTNERSHIPS

5 SYSTEM INCENTIVES
INCENTIVES FOR PATIENT PARTICIPATION
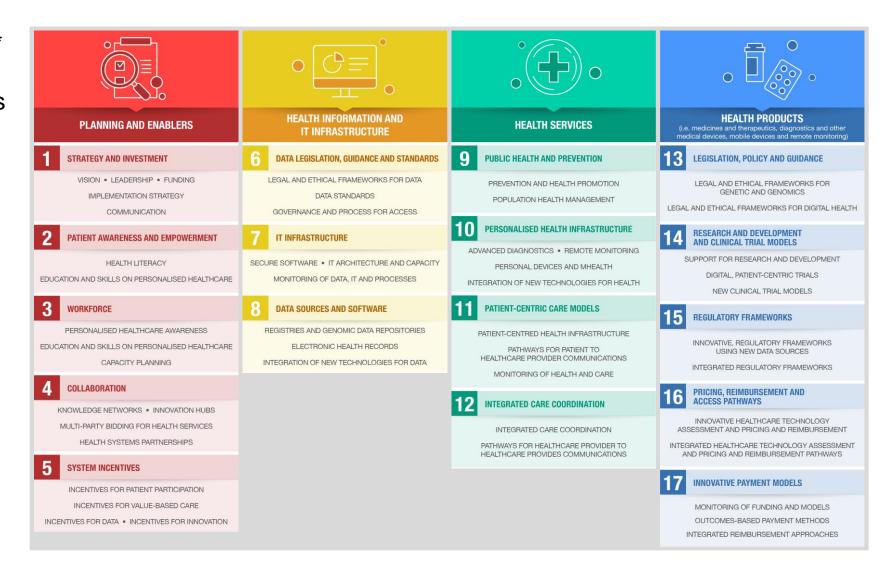INCENTIVES FOR VALUE-BASED CARE
INCENTIVES FOR DATA • INCENTIVES FOR INNOVATION

HEALTH INFORMATION AND IT INFRASTRUCTURE

6 DATA LEGISLATION, GUIDANCE AND STANDARDS
LEGAL AND ETHICAL FRAMEWORKS FOR DATA
DATA STANDARDS
GOVERNANCE AND PROCESS FOR ACCESS

7 IT INFRASTRUCTURE
SECURE SOFTWARE • IT ARCHITECTURE AND CAPACITY
MONITORING OF DATA, IT AND PROCESSES

8 DATA SOURCES AND SOFTWARE
REGISTRIES AND GENOMIC DATA REPOSITORIES
ELECTRONIC HEALTH RECORDS
INTEGRATION OF NEW TECHNOLOGIES FOR DATA

HEALTH SERVICES

9 PUBLIC HEALTH AND PREVENTION
PREVENTION AND HEALTH PROMOTION
POPULATION HEALTH MANAGEMENT

10 PERSONALISED HEALTH INFRASTRUCTURE
ADVANCED DIAGNOSTICS • REMOTE MONITORING
PERSONAL DEVICES AND MHEALTH
INTEGRATION OF NEW TECHNOLOGIES FOR HEALTH

11 PATIENT-CENTRIC CARE MODELS
PATIENT-CENTRED HEALTH INFRASTRUCTURE
PATHWAYS FOR PATIENT TO HEALTHCARE PROVIDER COMMUNICATIONS
MONITORING OF HEALTH AND CARE

12 INTEGRATED CARE COORDINATION
INTEGRATED CARE COORDINATION
PATHWAYS FOR HEALTHCARE PROVIDER TO HEALTHCARE PROVIDES COMMUNICATIONS

HEALTH PRODUCTS
(i.e. medicines and therapeutics, diagnostics and other medical devices, mobile devices and remote monitoring)

13 LEGISLATION, POLICY AND GUIDANCE
LEGAL AND ETHICAL FRAMEWORKS FOR GENETIC AND GENOMICS
LEGAL AND ETHICAL FRAMEWORKS FOR DIGITAL HEALTH

14 RESEARCH AND DEVELOPMENT AND CLINICAL TRIAL MODELS
SUPPORT FOR RESEARCH AND DEVELOPMENT
DIGITAL, PATIENT-CENTRIC TRIALS
NEW CLINICAL TRIAL MODELS

15 REGULATORY FRAMEWORKS
INNOVATIVE, REGULATORY FRAMEWORKS USING NEW DATA SOURCES
INTEGRATED REGULATORY FRAMEWORKS

16 PRICING, REIMBURSEMENT AND ACCESS PATHWAYS
INNOVATIVE HEALTHCARE TECHNOLOGY ASSESSMENT AND PRICING AND REIMBURSEMENT
INTEGRATED HEALTHCARE TECHNOLOGY ASSESSMENT AND PRICING AND REIMBURSEMENT PATHWAYS

17 INNOVATIVE PAYMENT MODELS
MONITORING OF FUNDING AND MODELS
OUTCOMES-BASED PAYMENT METHODS
INTEGRATED REIMBURSEMENT APPROACHES

Three topics were identified as the most actionable for health advocates and people affected by health conditions

Personalised Healthcare Building Blocks Framework

Based on the elements that make up personalised healthcare, three core topics spanning multiple Building Blocks have been identified in which health advocates can take action

Personalised Healthcare Literacy Building & Empowerment

Increasing understanding of what personalised healthcare is and the benefits for people affected by health conditions. Empowering health advocates to work towards personalised healthcare solutions

Ecosystem Development & Policy

Embedding the views of people affected by health conditions in clinical research, care delivery plans, regulatory and public health policy frameworks, as well as pricing/reimbursement/access pathways for personalised healthcare

Data & Digitalisation of Healthcare

Improving collaborations with health advocates in developing legislation, standards and guidance for health data and digital solutions to personalise health

*The topics, taken from the Building Blocks framework, have been explored and developed following recommendations and feedback from Roche Personalised Healthcare Global Patient Council

Select a topic to begin

Personalised Healthcare Literacy Building & Empowerment

Increasing understanding of what personalised healthcare is and the benefits for people affected by health conditions. Empowering health advocates to work towards personalised healthcare solutions

Ecosystem Development & Policy

Embedding views of people affected by health conditions in clinical research, care delivery plans and regulatory/health policy frameworks

Data & Digitalisation of Healthcare

Improving collaborations with health advocates in developing legislation, standards and guidance for health data and digital solutions to personalise health

Personalised Healthcare Literacy Building & Empowerment

Personalised Healthcare Literacy Building & Empowerment	Ecosystem Development & Policy	Data & Digitalisation of Healthcare

DESIRED OUTCOME

Communities have a deep understanding of personalised healthcare and are engaged in regular dialogue with key stakeholders that leads to action towards personalised healthcare

ACTION AREAS: READ MORE ABOUT…

…increasing general understanding of personalised healthcare, its key components and benefits in my community

…increasing understanding of specific personalised healthcare topics (e.g. prevention, health data, etc.) in my community

…improving dialogues between healthcare providers, people affected by health conditions and others to enable shared decision making

…empowering communities to act as key stakeholders in developing personalised healthcare-enabled health systems

IMPLEMENTATION ACTIVITIES

GUIDANCE AND TOOLS 1 2
BEST PRACTICE EXAMPLES 1 2

GUIDANCE AND TOOLS 1
BEST PRACTICE EXAMPLES 1

GUIDANCE AND TOOLS 1 2
BEST PRACTICE EXAMPLES 1 2

GUIDANCE AND TOOLS 1 2 3 4
BEST PRACTICE EXAMPLES 1 2 3 4

Increasing general understanding of personalised healthcare

Implementation activity

1 **Launching awareness and educational personalised healthcare campaigns describing how personalised healthcare changes care for people affected by health conditions, and emphasising its benefits**

2

Who benefits?

- People affected by health conditions
- Health advocates

GUIDANCE AND TOOLS   BEST PRACTICE EXAMPLES

Find out…

○ **What personalised healthcare is and how to talk to people affected by health conditions about it**

- **Infographic** (Personalised Healthcare Toolkit for the Patient Community)
  Infographic outlining what personalised healthcare is and what it means for people affected by health conditions

- **Frequently Asked Questions** (Personalised Healthcare Toolkit for the Patient Community)
  Frequently asked questions about topics in personalised healthcare, for people affected by health conditions

- **Glossary** (Personalised Healthcare Toolkit for the Patient Community)
  Glossary of terms frequently used in conversations about personalised healthcare

○ **How to communicate the benefits of personalised healthcare with people affected by health conditions**

- **Presentation deck** (Personalised Healthcare Toolkit for the Patient Community)
  Editable slide deck covering the value of personalised healthcare for people affected by health conditions

- **Factsheet** (Personalised Healthcare Toolkit for the Patient Community)
  Factsheet outlining the benefits of personalised healthcare towards individual care and wider societal value

- **And the above tools!**

Increasing general understanding of personalised healthcare

Implementation activity

1 **Launching awareness and educational personalised healthcare campaigns describing how personalised healthcare changes care for people affected by health conditions, and emphasising its benefits**
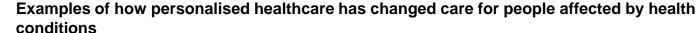
2

Who benefits?

- People affected by health conditions
- Health advocates

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **Examples of how personalised healthcare has changed care for people affected by health conditions**

- **Personal stories** (*Pharmaphorum*)
  Unique perspectives of personalised medicine in practice from people affected by health conditions

- **Blog** (Personalized Medicine Coalition)
  A perspective on accelerating personalisation of cancer treatment from someone personally affected by the condition

JUMP TO NEXT ACTION AREA

Personalised Healthcare Literacy Building & Empowerment

Increasing general understanding of personalised healthcare

Implementation activity

1 Embedding personalised healthcare information in awareness campaigns on prevention and health promotion, especially during world awareness days

2

Who benefits?

- People affected by health conditions
- Population at large

BEST PRACTICE EXAMPLES

Find out…

○ **Visual assets that communicate personalised healthcare topics for my campaign**

- **Infographic** (Personalised Healthcare Toolkit for the Patient Community)
  Infographic outlining what personalised healthcare is and what it means for people affected by health conditions

○ **Editable slide content to communicate the value of personalised healthcare**

- **Presentation deck** (Personalised Healthcare Toolkit for the Patient Community)
  Editable slide deck covering the value of personalised healthcare for people affected by health conditions

○ **Website-ready resources to communicate about personalised healthcare with my community**

- **Factsheet** (Personalised Healthcare Toolkit for the Patient Community)
  Factsheet outlining the benefits of personalised healthcare towards individual care and wider societal value

- **Frequently Asked Questions** (Personalised Healthcare Toolkit for the Patient Community)
  Frequently asked questions for people affected by health conditions about topics in personalised healthcare

- **And the above tools!**

○ **General guidance for writing content for people with health conditions**

- **Webinar** (Workgroup of European Cancer Patient Advocacy Networks)
  How to develop good content and materials for people affected by health conditions - print, online and video

JUMP TO NEXT ACTION AREA

Increasing general understanding of personalised healthcare

Implementation activity

1 **Embedding personalised healthcare information in awareness campaigns on prevention and health promotion, especially during world awareness days**

2

Who benefits?

- People affected by health conditions
- Population at large

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **Examples of successful campaigns that share disease-specific personalised healthcare information**

- **Campaign** (ECPC)
  Personalised Medicine Awareness Month: Cracking the Cancer Code

- **Campaign** (ECPC)
  Molecular Testing & Personalised Medicine

- **Campaign** (LUNGEVITY)
  Biomarker testing awareness campaign: No One Missed

- **Campaign** (Colorectal Cancer Canada)
  Biomarker testing awareness campaign: Get Personal

JUMP TO NEXT
ACTION AREA

Increasing understanding of specific personalised healthcare topics

1 Educating others and advocating for personalised healthcare-related topics, such as advanced diagnostics and data sharing/security

Who benefits?

- People affected by health conditions
- Health advocates

GUIDANCE AND TOOLS   BEST PRACTICE EXAMPLES

Find out…

○ **More information on biomarkers and molecular diagnostics**

- **Background information – molecular diagnostics** (Personalized Medicine Coalition)
  Introduction to molecular diagnostics and its role in personalised healthcare

- **Background information - biomarkers** (Personalised Medicine Coalition)
  Introduction to types of biomarkers – predisposition, diagnostic, prognostic and predictive

- **Infographic – molecular diagnostics** (European Cancer Patient Coalition)
  Educating and empowering people affected by health conditions regarding the potential and availability of molecular testing

- **Infographic - biomarkers** (European Alliance for Personalised Medicine)
  Education on biomarkers and awareness of their use across Europe

○ **More information on genetic testing and associated considerations**

- **Guide** (Personalised Medicine Coalition)
  Consumer's Guide to Genetic Health Testing describes what genetic tests are, outlines the types of information the tests can provide, and explains what consumers should consider before ordering an at-home genetic test directly from a genetic testing company

Increasing understanding of specific personalised healthcare topics

Implementation activity

1 **Educating others and advocating for personalised healthcare-related topics, such as advanced diagnostics and data sharing/security**

Who benefits?

- People affected by health conditions
- Health advocates

GUIDANCE AND TOOLS   BEST PRACTICE EXAMPLES

Find out…

○ **More information on the importance of data sharing, and address potential concerns around giving consent and data security**

- **Background information** (University of Illinois)
  Strategies for improving cybersecurity around data collection in healthcare

- **Background information** (American Cancer Society)
  Information on informed consent and data sharing for people affected by health conditions, including carers

- **Videos** (Personalised Healthcare Toolkit for the Patient Community)

  Videos from the International Experience Exchange with Patient Organisations (IEEPO) 'hot topics in personalised healthcare' series, involving health advocacy leaders discussing topics such as generating and managing data, building trust and confidence in it, using it to monitor health and make clinical decisions, the value of electronic health records and augmented intelligence and machine learning in digital health

- **Background information** (Department of Health and Human Services USA)
  Resource sheets containing information on health information rights, the benefits of electronic health records and how they are kept secure under United States federal legislation

- **Background information** (European Patients Forum)
  Guidance for patients and patient organisations on personal data protection in the European Union

Increasing understanding of specific personalised healthcare topics

Implementation activity

1 **Educating others and advocating for personalised healthcare-related topics, such as advanced diagnostics and data sharing/security**

Who benefits?

- People affected by health conditions
- Health advocates

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **More information on the importance of digital health literacy in an increasingly digital world**

- **Information sheet** (EuroHealthNet)
  Guide describing latest developments within digital health literacy, with examples from member organisations and suggestions on how further progress could be made across Europe

○ **Examples of successful materials that educate on specific personalised healthcare topics**

- **Video** (Leukaemia and Lymphoma society)
  Explains what personalised medicine is and how molecular profiling is being used to help healthcare professionals better understand a person's diagnosis

- **Toolkit** (International Alliance of Patients' Organizations)
  Explains what cell and gene therapy is, including benefits for patients, myths and facts, emerging issues and regulatory challenges

JUMP TO PREVIOUS OR NEXT ACTION AREA

Improving dialogues between healthcare providers, people affected by health conditions and others to enable shared decision making

Implementation activity

1 Developing training modules and materials on communication between people affected by health conditions and healthcare providers to foster shared decision making

2

Who benefits?

- People affected by health conditions
- Healthcare providers

GUIDANCE AND TOOLS   BEST PRACTICE EXAMPLES

Find out…

○ **What shared decision making is and how it can benefit people affected by health conditions**

- **Background information** (Patients Association UK)
  Information and frequently asked questions on shared decision-making for people living with conditions and carers

- **Information video** (The Health Foundation)
  Information about the implementation of a shared decision-making initiative within the UK health system

- **Resource bank and tools** (Less is More Medicine)
  Shared decision-making sample conversations, handouts and videos

○ **How to implement shared decision making into clinical practice**

- **White paper** (The King's Fund)
  Report on why shared decision-making is important, why it may not currently be the norm, and steps for implementing it within a health system

- **White paper** (The Health Foundation)
  A review of evidence considering whether shared decision-making is worthwhile, including tools to support implementation

- **Toolkits** (Dartmouth-Hitchcock)
  Guidelines and tools for integrating decision support into care

Personalised Healthcare Literacy Building & Empowerment

Improving dialogues between healthcare providers, people affected by health conditions and others to enable shared decision making

Implementation activity

1 **2** Developing training modules and materials on communication between people affected by health conditions and healthcare providers to foster shared decision making

Who benefits?

- People affected by health conditions
- Healthcare providers

GUIDANCE AND TOOLS

BEST PRACTICE EXAMPLES

Read…

○ **Training programmes for people affected by health conditions, carers and staff on shared decision making**

- **Training programme**
  Different ways of encouraging shared decision making and spreading learning across the health care community

○ **Supporting materials to facilitate conversations between healthcare providers and people affected by health conditions to support shared decision making/personalised healthcare**

- **Consultation Guide** (Association of European Cancer Leagues)
  Guide for people affected by health conditions to help them communicate with healthcare providers

- **Checklist** (United Kingdom National Health Service)
  A checklist for people affected by health conditions, service users and carers to support shared decision making and collaborative care planning

- **Guide** (Personalized Medicine Coalition)
  Questions for people affected by health conditions to ask healthcare providers about personalised healthcare

- **Resource bank and tools** (Less is More Medicine)
  Shared decision-making sample conversations, handouts and videos

- **Medication decision aid** (Autism Speaks)
  Aid to comparing treatment options, including risks, benefits, personal values and questions to ask healthcare providers

Personalised Healthcare Literacy Building & Empowerment

Improving dialogues between healthcare providers, people affected by health conditions and others to enable shared decision making

Implementation activity

1 Developing training modules and materials on communication
2 between people affected by health conditions and healthcare providers to foster shared decision making

BEST PRACTICE EXAMPLES

Read…

○ **Supporting materials to facilitate conversations between healthcare providers and people affected by health conditions to support shared decision making/personalised healthcare**

- **Medical terms simplifier** (European Medicines Agency)
  Glossary containing plain-language descriptions of medical terms related to use of medicines

Who benefits?

- People affected by health conditions
- Healthcare providers

Improving dialogues between healthcare providers, people affected by health conditions and others to enable shared decision making

Implementation activity

1

2 Providing education and training to people affected by health conditions on the use of digital tools to enable personalised healthcare

Who benefits?

- People affected by health conditions
- Healthcare providers

GUIDANCE AND TOOLS BEST PRACTICE EXAMPLES

Find out…

○ **More information on the benefits of digital health tools**

- **Background information** (U.S. Food and Drug Administration)
  Information covering the benefits of digital health solutions

- **Background information** (Forbes)
  General information about digital health, including examples of how it could benefit people affected by health conditions

- **Report on the future of healthcare** (Deloitte)
  Report looking towards the future of healthcare, analysing current trends and offering recommendations for how to evolve healthcare provision and person-centred care to arrive at a fully personalised future

- **White paper** (Digital Health Workforce Academy)
  Report covering the evolution of healthcare technology, why digital health matters, key stakeholders and the future direction of digital health

Improving dialogues between healthcare providers, people affected by health conditions and others to enable shared decision making

Implementation activity

1 Providing education and training to people affected by health conditions on the use of digital tools to enable personalised healthcare

2

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **Examples of digestible ways to present the benefits of digitalisation**

- **Infographic** (European Commission)
  Harnessing the potential of data to empower citizens and build a healthier society

Who benefits?

- People affected by health conditions
- Healthcare providers

Empowering communities to act as key stakeholders in developing personalised healthcare-enabled health systems

Implementation activity

1 Providing educational support materials and tools for healthcare leaders to become strong advocates for personalised healthcare

2

3

4

Who benefits?

- Health advocates

GUIDANCE AND TOOLS   BEST PRACTICE EXAMPLES

Find out…

○ **The benefits of personalised healthcare for individuals and wider society**

- **Presentation deck** (Personalised Healthcare Toolkit for the Patient Community)
  Editable slide deck covering the value of personalised healthcare for people affected by health conditions

- **Factsheet** (Personalised Healthcare Toolkit for the Patient Community)
  Factsheet outlining the benefits of personalised healthcare towards individual care and wider societal value

- **Frequently Asked Questions** (Personalised Healthcare Toolkit for the Patient Community)
  Frequently asked questions for people affected by health conditions and carers about topics in personalised healthcare

○ **About advocacy, including how to create evidence for advocacy impact**

- **Background information** (European Centre for Disease Prevention and Control)
  Short description of health advocacy

- **Webinar** (Workgroup of European Cancer Patient Advocacy Networks)
  An introduction to evidence-based advocacy, and how to create evidence for advocacy impact

JUMP TO PREVIOUS ACTION AREA

Empowering communities to act as key stakeholders in developing personalised healthcare-enabled health systems

Implementation activity

1 **Providing educational support materials and tools for healthcare leaders to become strong advocates for personalised healthcare**

2

3

4

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **Examples of training in health advocacy**

- **Webinar** (Workgroup of European Cancer Patient Advocacy Networks)
  Introduction to presentation skills for health advocates

Who benefits?

- Health advocates

Empowering communities to act as key stakeholders in developing personalised healthcare-enabled health systems

Implementation activity

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Developing training material on how to map out, prepare for, and successfully engage with stakeholders (such as healthcare providers, policymakers and other health advocacy groups) to act as key partners in multi-stakeholder efforts to promote personalised healthcare

Who benefits?

- Health advocates

GUIDANCE AND TOOLS   BEST PRACTICE EXAMPLES

Find out…

○ **How to understand and engage with a broad group of different stakeholders**

- **How-to guide** (World Health Organization)
  Guidelines for mapping and understanding relevant health reform stakeholders

- **How-to guide** (Association of Project Management)
  10 key principles of general stakeholder engagement

- **Webinar** (Workgroup of European Cancer Patient Advocacy Networks, WECAN)
  An introduction to the healthcare ecosystem and stakeholder management

- **Background information** (World Health Organization)
  Information on the importance of engaging stakeholders in healthcare

- **Background information** (International Alliance of Patients' Organizations)
  Toolkit outlining how patients organisations, both large and small, can work effectively with a range of partners and stakeholders

Empowering communities to act as key stakeholders in developing personalised healthcare-enabled health systems

Implementation activity

1
2 Developing training material on how to map out, prepare for, and successfully engage with stakeholders (such as healthcare providers, policymakers and other health advocacy groups) to act as key partners in multi-stakeholder efforts to promote personalised healthcare
3
4

Who benefits?

- Health advocates

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **Examples of training materials for health advocates and people affected by health conditions**

- **Training resources** (European Medicines Agency)
  Training overviews and videos for health advocates and people affected by health conditions taking part in engagement activities with regulatory bodies, including involvement in scientific advisory groups

- **Short guide** (European Medicines Agency)
  Two-pager guide to support participation in scientific advice procedures

○ **Examples of engagement activities with wider health system stakeholders**

- **Patient Engagement Opportunities** (US Food and Drug Administration)
  Collection of groups, sessions and projects that actively involve people affected by health conditions in medical product development, clinical trial design and drug evaluation and regulation

JUMP TO PREVIOUS ACTION AREA

Personalised Healthcare Literacy Building & Empowerment

Empowering communities to act as key stakeholders in developing personalised healthcare-enabled health systems

Implementation activity

1
2
3 Developing guidance material and (peer-to-peer) trainings to support skills development of health advocates to provide input and/or co-create health services and products
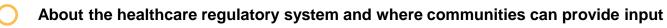**4**

Who benefits?

- People affected by health conditions
- Health advocates
- Healthcare providers

BEST PRACTICE EXAMPLES

Find out…

○ **About the healthcare regulatory system and where communities can provide input**

- **Webinar** (Workgroup of European Cancer Patient Advocacy Networks)
  An introduction to the healthcare regulatory system, including an overview of access pathways and why access to treatment, care and diagnostics can be an issue

- **Webinar** (Workgroup of European Cancer Patient Advocacy Networks)
  An introduction to how therapy development works, the development lifecycle, endpoints, trial design and engaging people affected by health conditions in research

Empowering communities to act as key stakeholders in developing personalised healthcare-enabled health systems

Implementation activity

1
2
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4

Developing guidance material and (peer-to-peer) trainings to support skills development of health advocates to provide input and/or co-create health services and products

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **Examples of how people affected by health conditions can input and help to personalise healthcare systems**

• **Online framework & toolkit** (Think Local Act Personal)
A framework to support improved personalised care and support for providers, commissioners and people who access services

Who benefits?

• People affected by health conditions
• Health advocates
• Healthcare providers

JUMP TO PREVIOUS ACTION AREA

Personalised Healthcare Literacy Building & Empowerment

Empowering communities to act as key stakeholders in developing personalised healthcare-enabled health systems

Implementation activity

1 Collect, share and map best practices against specific topics of interest/priorities and disease areas

2

3

4

GUIDANCE AND TOOLS   BEST PRACTICE EXAMPLES

Find out…

○ **About key topics for community involvement in personalised healthcare**

- **White paper** (Personalized Medicine Coalition)
  Report outlining the importance of a person-centred research agenda and identifying research topics to improve the delivery of personalised medicine in ways that are most meaningful to people living with conditions

- **Webinar** (Workgroup of European Cancer Patient Advocacy Networks)
  An introduction to outcomes reported by people affected by health conditions, and other measures and endpoints relevant for them

Who benefits?

- Population at large
- People affected by health conditions
- Health advocates

JUMP TO PREVIOUS ACTION AREA

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Empowering communities to act as key stakeholders in developing personalised healthcare-enabled health systems

Implementation activity

1
2
3
4

Collect, share and map best practices against specific topics of interest/priorities and disease areas

BEST PRACTICE EXAMPLES

Read…

○ **A resource bank of best practices for engaging with people affected by health conditions**

- **Book of good practices** (Patient Focussed Medicine Development)
  Practical tools to plan, assess and execute any community engagement initiative

- **Resource bank** (Patient Engagement Synapse)
  Discover the latest tools and resources for more meaningful engagement with people affected by health conditions

Who benefits?

- Population at large
- People affected by health conditions
- Health advocates

Personalised Healthcare Ecosystem Development & Policy

Personalised Healthcare Literacy Building & Empowerment	Ecosystem Development & Policy	Data & Digitalisation of Healthcare

DESIRED OUTCOME

ACTION AREAS: READ MORE ABOUT…

IMPLEMENTATION ACTIVITIES

People affected by health conditions can input into clinical research, care delivery plans and regulatory/health policy frameworks

▶ …how to input into regulatory frameworks and pricing/reimbursement/access pathways for personalised healthcare

GUIDANCE AND TOOLS — 1 2 3
BEST PRACTICE EXAMPLES — 1 2 3

▶ …strengthening shared decision making between people affected by health conditions and their doctors and/or healthcare team

GUIDANCE AND TOOLS — 1 2
BEST PRACTICE EXAMPLES — 1 2

▶ …participating in the co-creation of guidelines, services and clinical trials which are inclusive of people affected by health conditions

GUIDANCE AND TOOLS — 1 2
BEST PRACTICE EXAMPLES — 1 2

▶ …tracking quality of care and outcomes for people affected by health conditions

GUIDANCE AND TOOLS — 1
BEST PRACTICE EXAMPLES — 1

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How to input into regulatory frameworks and pricing/reimbursement/access pathways for personalised healthcare

Implementation activity

1 Developing a position paper and advocating to make access to, and funding of, personalised healthcare a priority for policy makers
2
3

GUIDANCE AND TOOLS BEST PRACTICE EXAMPLES

Find out…

○ **How to expand and advance personalised healthcare-related policy**

- **Strategic plan** (Personalised Medicine Coalition)
  A comprehensive overview of the Personalised Medicine Coalition's strategic plan and activities to advance personalised medicine policy

○ **How to write position papers for health and education**

- **Writing guide** (Ontario Medical Students Association)
  Templates and guidance on writing and submitting policy and position papers

Who benefits?

- Population at large
- People affected by health conditions
- Policy makers
- Regulators
- Payers

JUMP TO NEXT ACTION AREA

Ecosystem Development & Policy

How to input into regulatory frameworks and pricing/reimbursement/access pathways for personalised healthcare

Implementation activity

1 **Developing a position paper and advocating to make access to, and funding of, personalised healthcare a priority for policy makers**

2

3

BEST PRACTICE EXAMPLES

Read…

○ **Examples of a campaign advocating for early access to personalised medicine and research and development**

- **Campaign** (European Alliance for Personalised Medicine)
  The steps needed to build a system with people affected by health conditions placed centrally

○ **Examples of a campaign advocating for policy change on molecular testing and personalised medicine**

- **Campaign** (European Cancer Patient Coalition)
  Infographic, animation on biomarkers and event summary of campaign focusing on education, and the launch of the first Personalised Medicine Awareness Month

Who benefits?

- Population at large
- People affected by health conditions
- Policy makers
- Regulators
- Payers

JUMP TO NEXT ACTION AREA

How to input into regulatory frameworks and pricing/reimbursement/access pathways for personalised healthcare

Implementation activity

1
2

Setting up peer-to-peer exchanges and creating materials where people affected by health conditions can provide input

3

GUIDANCE AND TOOLS   BEST PRACTICE EXAMPLES

Find out…

○ **How to facilitate peer-to-peer learning in the health sector**

- **How-to Guide** (Effective Institutions Platform)
  User-friendly guide with information on how to engage in and generate effective peer-to-peer support and learning

Who benefits?

- Health advocates
- Experts

How to input into regulatory frameworks and pricing/reimbursement/access pathways for personalised healthcare

Implementation activity

1
2 Setting up peer-to-peer exchanges and creating materials where people affected by health conditions can provide input
3

GUIDANCE AND TOOLS **BEST PRACTICE EXAMPLES**

Read…

○ **A resource bank of previous learnings and engagement in Health Technology Assessment (HTA) decision making**

- **Resource bank** (European Patients Forum)
  Surveys of previous engagement of health organisations in HTA decision making including level and type of involvement and outcome

Who benefits?

- Health advocates
- Experts

JUMP TO NEXT ACTION AREA

How to input into regulatory frameworks and pricing/reimbursement/access pathways for personalised healthcare

Implementation activity

1
2
3

Providing input informed by those affected by conditions into regulatory/Health Technology Assessment (HTA) and pricing and reimbursement pathways

Who benefits?

- Policy makers
- Regulators
- Payers

GUIDANCE AND TOOLS   BEST PRACTICE EXAMPLES

Find out…

○ **How to advocate for HTA processes incorporating input from those affected by conditions**

- **Policy Briefing** (International Alliance of Patient Organisations)
  Key arguments on the value of input from those affected by conditions in HTA processes

- **Position Paper** (Workgroup of European Cancer Patient Advocacy Networks)
  The advances of further EU integration of HTA, and considerations around meaningful input from people affected by conditions

○ **How to provide input into HTA decision making**

- **Webinar** (European Patients' Academy)
  Guidance on involvement in regulatory processes and the best approach for interaction with relevant authorities

- **Toolkit** (European Patients' Academy)
  Areas for involvement in HTA decision-making and guidance on stages of input

- **How-to guide** (Treat-NMD Neuromuscular Network)
  Guidance on how to set up a registry to collect information from people affected by conditions that can inform input in to HTA processes

- **Whitepaper** (Consumers Health Forum of Australia)
  Guidance and recommendations on the role of consumers and consumer advocacy in transforming healthcare ecosystems

Ecosystem Development & Policy

How to input into regulatory frameworks and pricing/reimbursement/access pathways for personalised healthcare

Implementation activity

1
2
3
Providing input informed by those affected by conditions into regulatory/Health Technology Assessment (HTA) and pricing and reimbursement pathways

Who benefits?

- Policy makers
- Regulators
- Payers

GUIDANCE AND TOOLS

BEST PRACTICE EXAMPLES

Read…

○ **Examples of previous input in HTA decision making**

- **Report** (EUnetHTA)
  Details of input from people affected by health conditions into The European Network for Health Technology Assessment (EUnetHTA) Relative Effectiveness Assessments

- **GetReal** (Innovative Medicines Initiative)
  Examples of using robust new methods of real world evidence collection earlier in research and development and the healthcare decision-making process

- **Patient Values Project** (Colorectal Cancer Canada)
  Project to define values of people affected by health conditions and measure and assign a weight to these values in cancer drug treatment to ensure their voices are heard in the evaluation of cancer care and the reimbursement of cancer drugs by public agencies.

Strengthening shared decision making between people affected by health conditions and their doctors and/or healthcare team

Implementation activity

1
2

Advocating for embedding the needs and expectations of people affected by health conditions into integrated care

GUIDANCE AND TOOLS

BEST PRACTICE EXAMPLES

Find out…

○ **The value of providing integrated care across the health care system**

- **Toolkit** (UK Local Government Association)
  Toolkit containing evidence and the positive impact of different integrated care models on people with health conditions, as well as the associated impact on activity and cost to different parts of the health and care system

- **Resource bank** (*The British Medical Journal*)
  Podcasts, reports and papers on the benefits of care centred on the individual and disease specific case-studies

Who benefits?

- People affected by health conditions
- Health advocates
- Healthcare professionals

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Strengthening shared decision making between people affected by health conditions and their doctors and/or healthcare team
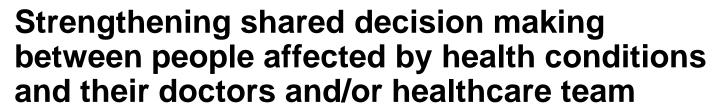
Implementation activity

1

2

Advocating for embedding the needs and expectations of people affected by health conditions into integrated care

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **Case studies of personalised healthcare and support planning**

• **Case studies** (*The British Medical Journal*)
  Videos explaining the approach to support planning and care focused on the individual

○ **An example position paper advocating for integrated care**

• **Consultation** (European Patients Forum)
  Input into the development of the European Union's Beating Cancer Plan detailing the importance of integrated care coordination and a multisectoral approach

Who benefits?

• People affected by health conditions
• Health advocates

JUMP TO PREVIOUS OR NEXT ACTION AREA

Strengthening shared decision making between people affected by health conditions and their doctors and/or healthcare team

Implementation activity

1 **Providing tools to facilitate conversations between those affected by a condition and their doctors/healthcare team regarding their care, treatment plan and self management**

2

GUIDANCE AND TOOLS   BEST PRACTICE EXAMPLES

Find out…

○ **Useful resources to help facilitate a conversation between people affected by health conditions and their doctors and/or healthcare team around shared decision making**

   • **Resource bank** (Less is More Medicine)
     Shared decision-making sample conversations, handouts and videos

   • **Toolkits** (Dartmouth)
     Guidelines and tools for integrating decision support into care and online training resources

○ **A guide for shared decision making and how to achieve it**

   • **Step-by-step guide** (Asthma and Allergy Network)
     Guide for shared decision making and its benefits for people living with asthma, including surveys on treatments for those affected by the condition
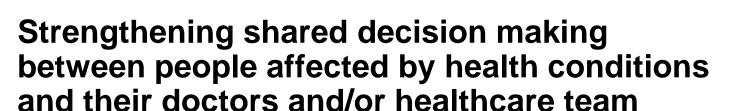
Who benefits?

• People affected by health conditions
• Healthcare professionals

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Strengthening shared decision making between people affected by health conditions and their doctors and/or healthcare team

Implementation activity

1 **2** **Providing tools to facilitate conversations between those affected by a condition and their doctors/healthcare team regarding their care, treatment plan and self management**

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **A case study showcasing the benefits of shared decision making and how to achieve it**

- **Step-by-step guide** (Asthma and Allergy Network)
  Guide for shared decision making and its benefits for people living with asthma, including surveys on treatments for those affected by the condition

Who benefits?

- People affected by health conditions
- Healthcare professionals

JUMP TO PREVIOUS OR NEXT ACTION AREA

Ecosystem Development & Policy

Participating in the co-creation of guidelines, services and clinical trials which are inclusive of people affected by health conditions

Implementation activity

1
2 Develop training for advocates to enable them to bring their expertise into the guideline, service development and research setting

Who benefits?

- Health advocates
- Experts
- Researchers
- Policy makers

BEST PRACTICE EXAMPLES

Find out…

○ **How to build skills for advocacy in the research agenda**

- **Training Academy** (Patients' Academy for Research Advocacy)

  Opportunity for healthcare organisations to partner with the Patients' Academy for Research Advocacy to train advocates and help them engage in research as full partners with a unique ability to advance science and medicine

- **Open Academy** (European Organisation for Rare Diseases)

  Training to empower advocates to participate in discussions with researchers, policy makers and companies on research and development

○ **How the perspectives of people affected by health conditions are taken into account in the design of clinical trials**

- **Toolkit** (TransCelerate)

  Comprehensive set of materials with a guide for engagement between people affected by conditions and stakeholders during clinical trial protocol development. The goal of this engagement is to improve experience and reduce burden for study participants

Participating in the co-creation of guidelines, services and clinical trials which are inclusive of people affected by health conditions

Implementation activity

1 **2** **Develop training for advocates to enable them to bring their expertise into the guideline, service development and research setting**

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **Research that can help advance personalised medicine**

- **Research Agenda** (Personalized Medicine Coalition)
  A research agenda for advancing personalised medicine with 45 research questions across nine areas of special concern for people affected by a condition

Who benefits?

- Health advocates
- Experts
- Researchers
- Policy makers

Participating in the co-creation of guidelines, services and clinical trials which are inclusive of people affected by health conditions

Implementation activity

1	**Setting up peer-to-peer exchange to build capabilities and leverage learning from experienced PAGs, experts and other organisations on multi-stakeholder partnerships**
2	

GUIDANCE AND TOOLS   BEST PRACTICE EXAMPLES

Find out…

○ **How to facilitate peer-to-peer learning in the health sector**

- **How-to Guide** (Effective Institutions Platform)
  User-friendly guide with information on how to engage in and generate effective peer-to-peer support and learning

○ **How to set up a platform for a peer-to-peer exchange**

- **Webinar and Factsheet** (European Organisation for Rare Diseases)
  Guidance on starting a Community Advisory Group to discuss the latest developments and challenges related to medical treatments under development

Who benefits?

- People affected by health conditions
- Health advocates
- Experts

Participating in the co-creation of guidelines, services and clinical trials which are inclusive of people affected by health conditions

Implementation activity

1
2
Setting up peer-to-peer exchange to build capabilities and leverage learning from experienced PAGs, experts and other organisations on multi-stakeholder partnerships

Who benefits?

- People affected by health conditions
- Health advocates
- Experts

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **Case studies and learnings from people affected by health conditions previously involved in research**

- **Guide** (Innovative Medicines Initiative)
  Interviews and guidance for the involvement of people affected by health conditions in research, including advice and examples of projects with strong involvement of people affected by health conditions

- **Best practices** (BioMed Central)
  Best practices in involving people affected by health conditions in an EU project, including key principles for success

- **Research initiatives** (Crohn's & Colitis Foundation)
  Initiatives to centralise and integrate biosamples and form network of experts. Includes community-powered research network and an online registry with more than 15,000 adults affected by IBD from across Australia

- **OneNeurology** (European Federation of Neurological Associations and the European Academy of Neurology)
  The OneNeurology initiative aims to unite and strengthen neurology-related groups to stimulate collaborative advocacy, action and accountability for the prevention, treatment and management of neurological disorders worldwide.

Tracking quality of care and outcomes for people affected by health conditions

Implementation activity

1 **Advocating for and providing input to define key performance indicators for personalised healthcare that matter to people affected by conditions incl. e.g. quality of life or reported outcomes to track and improve quality of care delivered**

GUIDANCE AND TOOLS   BEST PRACTICE EXAMPLES

Find out…

◯ **How to create a healthcare system focused on the people affected by a condition**

- **Paper** (Cleveland Clinic)
  Guidance on the steps needed to transform into a healthcare system focussed on individuals affected by a condition

◯ **How to create a registry incorporating key performance indicators that matter to those affected by a condition**

- **Registry** (Agency for Healthcare Research and Quality)
  User guide for incorporating perspectives from those affected by a condition in registries evaluating outcomes

Who benefits?

- People affected by health conditions
- Policy makers
- Regulators
- Payers
- Healthcare providers

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JUMP TO PREVIOUS ACTION AREA

Tracking quality of care and outcomes for people affected by health conditions

Implementation activity

1 **Advocating for and providing input to define key performance indicators for personalised healthcare that matter to people affected by conditions incl. e.g. quality of life or reported outcomes to track and improve quality of care delivered**

Who benefits?

- People affected by health conditions
- Policy makers
- Regulators
- Payers
- Healthcare providers

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **Examples of indicators and outcomes focused on the individuals affected by a condition**

- **Review** (The British Medical Journal / International Alliance of Patients' Organizations)
  Reviews of existing indicators and outcomes

- **Webinar** (Workgroup of European Cancer Patient Advocacy Networks)
  An introduction to outcomes reported by people affected by health conditions and other measures and endpoints relevant for people living with conditions

○ **How to evaluate current health systems and investigate if they are sustainable and personalised**

- **Future Proofing Healthcare** (Roche)
  Benchmarking health systems and harnessing expert opinions to make them resilient and personalised

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Data & Digitalisation of Healthcare

Personalised Healthcare Literacy Building & Empowerment	Ecosystem Development & Policy	Data & Digitalisation of Healthcare

DESIRED OUTCOME

ACTION AREAS: READ MORE ABOUT…

IMPLEMENTATION ACTIVITIES

People affected by health conditions collaborate in setting:
- Frameworks for regulating digital healthcare
- Standards and guidance on data collection and best use of high-quality, accessible data sources
- Accessible digital solutions to personalise health

…integrating the perspectives of people affected by health conditions into standards and policies regarding data privacy and sharing

GUIDANCE AND TOOLS |1| |2|
BEST PRACTICE EXAMPLES |1| |2|

…standardising legal and ethical frameworks on digital health once perspectives of people affected by health conditions have been integrated

GUIDANCE AND TOOLS |1| |2| |3|
BEST PRACTICE EXAMPLES |1| |2| |3|

…assimilating preferences of people affected by health conditions into design and definition of electronic health records, real world data and artificial intelligence

GUIDANCE AND TOOLS |1| |2|
BEST PRACTICE EXAMPLES |1| |2|

…empowering people affected by health conditions to actively use mobile health devices and electronic monitoring for management of their own care

GUIDANCE AND TOOLS |1| |2|
BEST PRACTICE EXAMPLES |1| |2|

Data & Digitalisation of Healthcare

Integrating the perspectives of people affected by health conditions into standards and policies regarding data privacy and sharing

Implementation activity

1 **Conduct research amongst the community to explore their perspectives on data sharing and protection**

2

Who benefits?

- Policy makers
- Health advocates
- People affected by health conditions

BEST PRACTICE EXAMPLES

Find out…

○ **How to conduct my own research within my community**

- **How-to guide** (Survey Monkey)
  Advice on conducting and getting the best participation in medical surveys

- **Research** (European Journal of Human Genetics)
  Information on what motivates research participants to share their own health data, and equally their concerns in doing so

- **How-to guide** (Workgroup of European Cancer Patient Advocacy Networks)
  Information on how to generate data, including data generated via technology from people affected by health conditions

Integrating the perspectives of people affected by health conditions into standards and policies regarding data privacy and sharing

Implementation activity

1

2

Conduct research amongst the community to explore their perspectives on data sharing and protection

BEST PRACTICE EXAMPLES

Read…

○ **Examples of research into the perspectives of people affected by health conditions on data sharing**

- **Research** (European Organisation for Rare Diseases)
  Survey of perspectives on data sharing and protection in the rare disease community

- **Research** (European Patients Forum)
  Survey gathering the perspectives of people affected by health conditions on the use of electronic health records

- **Research** (Data Saves Lives)
  Public opinions and behaviour around health data

Who benefits?

- Policy makers
- Health advocates
- People affected by health conditions

Integrating the perspectives of people affected by health conditions into standards and policies regarding data privacy and sharing

Implementation activity

1 **2** **Develop evidence-based advocacy campaigns for integrating perspectives of people affected by health conditions into standards / policies regarding data privacy and sharing**
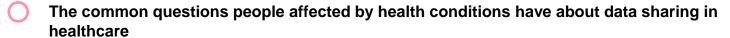
Who benefits?

- Policy makers
- Healthcare providers
- Researchers
- Health advocates
- People affected by health conditions
- Population at large

GUIDANCE AND TOOLS   BEST PRACTICE EXAMPLES

Find out…

○ **The common questions people affected by health conditions have about data sharing in healthcare**

- **Frequently asked questions** (Personalised Healthcare Toolkit for the Patient Community)

   Frequently asked questions for people affected by health conditions including data sharing and security in personalised healthcare

○ **How to create an advocacy campaign around digital and data policies**

- **How-to guide** (Workgroup of European Cancer Patient Advocacy Networks)

   Information on creating an evidence-based advocacy campaign and generating data, including data collected via technology from people affected by health conditions

JUMP TO NEXT ACTION AREA

Integrating the perspectives of people affected by health conditions into standards and policies regarding data privacy and sharing

Implementation activity

1

2 Develop evidence-based advocacy campaigns for integrating perspectives of people affected by health conditions into standards / policies regarding data privacy and sharing

Who benefits?

- Policy makers
- Healthcare providers
- Researchers
- Health advocates
- People affected by health conditions
- Population at large

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **Examples of people affected by health conditions and advocates directly advocating for improved management and sharing of health data**

- **Letter** (Society for Participatory Medicine)
  Letter from people affected by health conditions, carers and advocates highlighting the importance of people being given autonomy over their own health data, including case studies where people could have benefitted from better data management and where they were able to manage conditions well due to good data management

○ **Examples of guidance developed to help organisations or individuals provide, store, access, manage or otherwise use health-related data**

- **Toolkit** (Global Alliance for Genomics & Health)
  Framework for the responsible sharing of genomic and health-related data guided by human rights, including the right to benefit from the progress of science, as well as privacy, non-discrimination, and procedural fairness

○ **Examples of where healthcare organisations have successfully helped change policy around health data**

- **Press release** (European Alliance for Personalised Medicine)
  Information about the contributions made by the organisation to the development of European General Data Protection Regulation (GDPR) legislation

JUMP TO NEXT ACTION AREA

Standardising legal and ethical frameworks on digital health once perspectives of people affected by health conditions have been integrated

Implementation activity

1 **2** **3** **(Co-)develop and use training materials for health advocates that enable them to provide input into legal and ethical frameworks on digital health**

Who benefits?

- Health advocates
- People affected by health conditions
- Policy makers
- Regulators

GUIDANCE AND TOOLS   BEST PRACTICE EXAMPLES

Find out…

○ **Why data sharing in personalised healthcare is important**

- **Presentation deck** (Personalised Healthcare Toolkit for the Patient Community)
  Editable slide deck covering the value of personalised healthcare for people affected by health conditions

○ **The importance of user input into digital health legal and ethical frameworks**

- **Whitepaper** (IQVIA)
  Whitepaper examining the importance of the voices of people affected by health conditions, and approaches to incorporating these voices in healthcare decision making

○ **Providing, storing, accessing, managing or otherwise using health-related data**

- **Whitepaper** – subscription only (HIMSS Analytics)
  Framework for education on digital health and strategy to work towards a digitally-enabled health system

- **Toolkit** (Global Alliance for Genomics & Health)
  Data security framework for the responsible sharing of genomic and health-related data guided by human rights, including the right to benefit from the progress of science, as well as privacy, non-discrimination, and procedural fairness

Standardising legal and ethical frameworks on digital health once perspectives of people affected by health conditions have been integrated

Implementation activity

1 **(Co-)develop and use training materials for health advocates that enable them to provide input into legal and ethical frameworks on digital health**

2

3

Who benefits?

- Health advocates
- People affected by health conditions
- Policy makers
- Regulators

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **Examples of training materials that raise awareness and empower health advocates in data regulation**

- **Webinars** (The Digital Health Society)
  Round tables exploring in-depth issues surrounding health data and the creation of the European Health Data Space

○ **Examples of existing digital health initiatives your organisation could join**

- **Global Network** (European Connected Health Alliance)
  Through this initiative, member organisations can grow their networks, promote their organisation, connect with innovators in digital health and collaborate globally to transform health and social care

Standardising legal and ethical frameworks on digital health once perspectives of people affected by health conditions have been integrated

Implementation activity

1
2 **Provide input informed and validated by people affected by health conditions into development of legal and ethical frameworks on digital health**
3

Who benefits?

- Policy makers
- Regulators
- Health advocates
- People affected by health conditions
- Population at large

GUIDANCE AND TOOLS   BEST PRACTICE EXAMPLES

Find out…

○ **The importance of user input into digital health legal and ethical frameworks**

- **Whitepaper** (IQVIA)
  Whitepaper examining the importance of the voices of people affected by health conditions, and approaches to incorporating these voices in healthcare decision making

○ **How to set up and manage data registries or biobanks**

- **Toolkit** (Treat-NMD Neuromuscular Network)
  Toolkit advising health organisations on the purpose of registries and how to set them up in terms of design, documentation and governance

- **How-to guide** (Workgroup of European Cancer Patient Advocacy Networks)
  Basic information about registries, how they can be set up by organisations, and their importance for people affected by health conditions, health advocacy and research

- **How-to video** (Genetic Alliance)
  Webinar exploring how two advocacy organisations set up registries and biobanks, including vendor selection, implementation and challenges faced

- **Toolkit** (Global Alliance for Genomics & Health)
  Data security framework for the responsible sharing of genomic and health-related data guided by human rights, including the right to benefit from the progress of science, as well as privacy, non-discrimination, and procedural fairness

Standardising legal and ethical frameworks on digital health once perspectives of people affected by health conditions have been integrated

Implementation activity

1
2 Provide input informed and validated by people affected by health conditions into development of legal and ethical frameworks on digital health
3

Who benefits?

- Policy makers
- Regulators
- Health advocates
- People affected by health conditions
- Population at large

GUIDANCE AND TOOLS **BEST PRACTICE EXAMPLES**

Read…

○ **Recommendations of how the perspectives of people affected by health conditions could be used to inform digital health and data sharing solutions**

- **Chain of Trust Project Report** (European Patients Forum)
  Report assessing the perspectives of the main end-users of digital health services across the EU, exploring how perceptions have changed and what barriers still exist to building confidence in and acceptance of this type of service delivery

- **Research** (European Organisation for Rare Diseases)
  Survey of perspectives on data sharing and protection in the rare disease community

- **Research** (European Patients Forum)
  Survey gathering perspectives of people affected by health conditions on the use of electronic health records

- **Research** (Data Saves Lives)
  Public opinions and behaviour around health data

JUMP TO PREVIOUS OR NEXT ACTION AREA

Data & Digitalisation of Healthcare

Standardising legal and ethical frameworks on digital health once perspectives of people affected by health conditions have been integrated

Implementation activity

1 2 3 Develop position papers and awareness campaigns to advocate for integration of the perspectives of people affected by health conditions into legal and ethical frameworks on digital health

Who benefits?

- Policy makers
- Health advocates
- People affected by health conditions
- Population at large

Find out…

○ **Writing position papers in healthcare and education**

- **Guidance** (Ontario Medical Students Association)
  Guidance and tips on writing effective policy or position papers, including an evaluation checklist

○ **The importance of user input into digital health legal and ethical frameworks**

- **Whitepaper** (IQVIA)
  Whitepaper examining the importance of the voices of people affected by health conditions, and approaches to incorporating these voices in healthcare decision making

Standardising legal and ethical frameworks on digital health once perspectives of people affected by health conditions have been integrated

Implementation activity

1
2
3

Develop position papers and awareness campaigns to advocate for integration of the perspectives of people affected by health conditions into legal and ethical frameworks on digital health
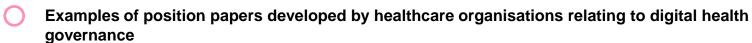
Who benefits?

- Policy makers
- Health advocates
- People affected by health conditions
- Population at large

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **Examples of position papers developed by healthcare organisations relating to digital health governance**

- **Position paper on digital health from the perspective of people affected by health conditions** (European Patient Innovation Summit)
  Position paper on digital health from the perspective of people affected by health conditions, developed using recommendations to transform development and uptake of digital health solutions, voted on by community representatives across Europe

- **Infographic on digital health from the perspective of people affected by health conditions** (European Patient Innovation Summit)
  Infographic summarising the above position paper on digital health from the perspective of people affected by health conditions, developed using recommendations to transform development and uptake of digital health solutions, voted on by community representatives across Europe

- **Position paper on the European Commission's Health Data Space** (European Patients Forum)
  Organisation input and response to the European Health Data Space 2021

- **Position paper on data sharing in the European Union** (European Patients Forum)
  Organisation input and response to the European Data Governance Act 2021

- **Position paper on the integration of self-management tools into routine care** (American Diabetes Association)
  Organisation position paper published in *Diabetes Care* supporting provision of diabetes self-management interventions to help people living with diabetes to make decisions about, and navigate, their own care

Data & Digitalisation of Healthcare

Assimilating preferences of people affected by health conditions into design and definition of electronic health records, real world data and artificial intelligence

Implementation activity

1
2

Provide input on preferences and requirements of people affected by health conditions regarding:

- **Access, use, amendment of electronic health records**
- **Real world data access, sharing and interoperability**
- **Artificial intelligence application**

Who benefits?

- Policy makers
- Health advocates
- Healthcare practitioners
- Researchers
- People affected by heath conditions

GUIDANCE AND TOOLS   BEST PRACTICE EXAMPLES

Find out…

○ **How to conduct health research now and in the future to acquire input on digital health from people affected by health conditions**

- **How-to guide** (Survey Monkey)
  Advice on conducting and getting the best participation in medical surveys

- **Review paper** (BioMed Central)
  Paper discussing how linking social media to electronic health records might allow better systematic collection of the views of people affected by health conditions as part of health services research

Data & Digitalisation of Healthcare

Assimilating preferences of people affected by health conditions into design and definition of electronic health records, real world data and artificial intelligence

Implementation activity

1
2

Provide input on preferences and requirements of people affected by health conditions regarding:

- **Access, use, amendment of electronic health records**
- **Real world data access, sharing and interoperability**
- **Artificial intelligence application**

Who benefits?

- Policy makers
- Health advocates
- Healthcare practitioners
- Researchers
- People affected by heath conditions

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **Examples of how to consult with the community on policy issues relating to digital health**

- **Consultation** (European Patients Forum)
  Coordinated response to the European Commission's 2020 digital strategy, by the organisation on behalf of members

- **Research** (European Patients Forum)
  Survey gathering perspectives of people affected by health conditions on the use of electronic health records

Data & Digitalisation of Healthcare

Assimilating preferences of people affected by health conditions into design and definition of electronic health records, real world data and artificial intelligence

Implementation activity

1 **2** **Raise awareness amongst the community around the importance of data, data sharing and advocate for integration of preferences of people affected by health conditions in frameworks and policies**

Who benefits?

- Policy makers
- Health advocates
- People affected by health conditions

BEST PRACTICE EXAMPLES

Find out…

○ **How to communicate about health data with people with health conditions**

- **Frequently asked questions** (Personalised Healthcare Toolkit for the Patient Community)
  Frequently asked questions for people affected by health conditions, including data sharing and security in personalised healthcare

○ **How to collect health data appropriately**

- **How-to guide** (Workgroup of European Cancer Patient Advocacy Networks)
  Information on how to generate data, including data generated via technology from people affected by health conditions

- **Research** (European Journal of Human Genetics)
  Information on what motivates research participants to share their own health data, and equally their concerns in doing so

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Assimilating preferences of people affected by health conditions into design and definition of electronic health records, real world data and artificial intelligence

Implementation activity

1 **2** **Raise awareness amongst the community around the importance of data, data sharing and advocate for integration of preferences of people affected by health conditions in frameworks and policies**

Who benefits?

- Policy makers
- Health advocates
- People affected by health conditions

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **Examples of how to communicate with people affected by health conditions about data sharing and data protection in healthcare**

- **Resource bank** (Data Saves Lives)
  Resources, case studies and educational materials on the benefits and importance of data in healthcare

○ **Examples of how healthcare organisations are advocating for person-centred digital health**

- **Position paper** (European Patients Forum)
  Position paper on mobile health in the European Union, including health literacy, self-management, data sharing, electronic health records and equitable access to eHealth

JUMP TO PREVIOUS OR NEXT ACTION AREA

Empowering people affected by health conditions to actively use mobile health devices and electronic monitoring for management of their own care
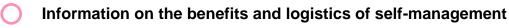
Implementation activity

1

2 Provide educational materials and resources to people affected by health conditions on the benefits of self-management and how new tools can support their care

Find out…

○ **Information on the benefits and logistics of self-management**

- **Information** (The Patients Association)
  Webpage outlining the benefits, tips and tools for self-management, including the common questions people have about it

○ **The different roles of people living with conditions in self-management**

- **Research** (California Health Care Foundation)
  A deep dive into the different roles played by different people affected by health conditions who are self-managing, including how different tools can support these roles

Who benefits?

- People affected by health conditions
- Carers of people affected by health conditions
- Healthcare providers

Data & Digitalisation of Healthcare

Empowering people affected by health conditions to actively use mobile health devices and electronic monitoring for management of their own care

Implementation activity

1 **2**

Provide educational materials and resources to people affected by health conditions on the benefits of self-management and how new tools can support their care

GUIDANCE AND TOOLS   **BEST PRACTICE EXAMPLES**

Read…

○ **Examples of successful shared decision making and self-management tools**

• **Health screening tools** (Allergy & Asthma Network)
   A guide to evidence-based shared decision making and examples developed for people affected by asthma and allergies

Who benefits?

• People affected by health conditions
• Carers of people affected by health conditions
• Healthcare providers

Data & Digitalisation of Healthcare

Empowering people affected by health conditions to actively use mobile health devices and electronic monitoring for management of their own care

Implementation activity

1 **Develop a position paper and awareness campaign on the relevance and importance of self-management**

2

Find out…

○ **Writing position papers in healthcare and education**

   • **Guidance** (Ontario Medical Students Association)
   Guidance and tips on writing effective policy or position papers, including an evaluation checklist

Who benefits?

- Policy makers
- Health advocates
- People affected by health conditions
- Healthcare providers

Empowering people affected by health conditions to actively use mobile health devices and electronic monitoring for management of their own care

Implementation activity

1

2 **Develop a position paper and awareness campaign on the relevance and importance of self-management**

Who benefits?

- Policy makers
- Health advocates
- People affected by health conditions
- Healthcare providers

GUIDANCE AND TOOLS **BEST PRACTICE EXAMPLES**

Read…

○ **Examples of clear position papers developed by healthcare organisations**

- **Position paper on the integration of self-management tools into routine care** (American Diabetes Association)
  Organisation position paper published in *Diabetes Care* supporting provision of diabetes self-management interventions to help people living with diabetes to make decisions about, and navigate, their own care

- **Position paper on self-management technology in type 1 diabetes** (Diabetes Australia)
  Organisation position paper stating people with diabetes should have choice and access to diabetes management solutions that help them manage their diabetes to the best of their ability

- **Position paper on self-management and supporting behaviour change** (Healthy Interactions)
  Organisation position paper on information sharing, peer support and clinical interventions needed to prepare individuals to engage with their personal health and self-management