Data Saves Lives

SURVEY RESULTS

Priority topics and tools for 2021

Prepared January 2021

#DataSavesLives

Overview

Following the Data Saves Lives (DSL) workshop 'Under the magnifying glass: 2020 in review and looking to 2021', held on Wednesday 9 December 2020, attendees and DSL advocates were invited to feedback on proposed focus areas for 2021.

This report details the results gathered via an online survey on the recommended editorial topics for DSL activities this year, to be explored through monthly guest blogs on our website, panel chats in live webinars and tweet chats, contributor video clips, patient stories etc. It also outlines the recommended tools to be included in our patient-group focused toolkit, to support patient groups in the best practice communication of health data initiatives.
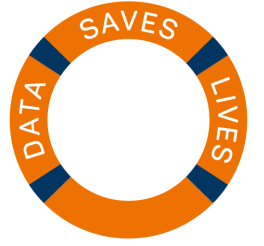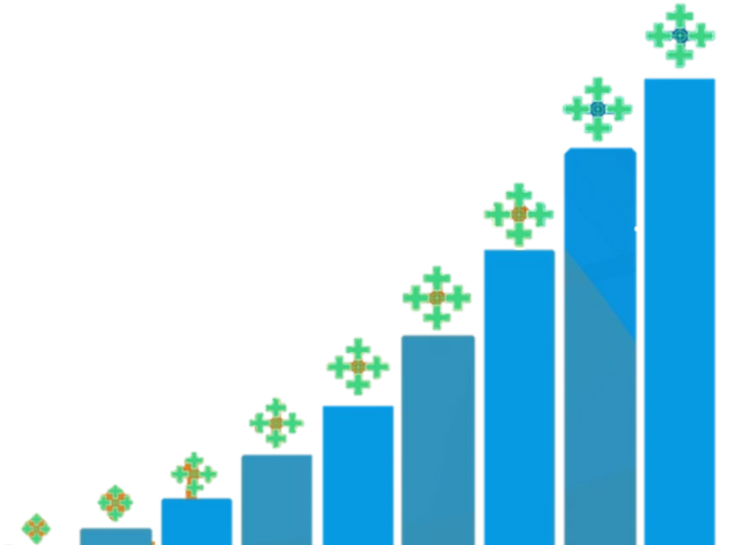
Priority topics for our editorial

Editorial areas

- There are three main areas of discussion in the health data space:
  - Ethics (e.g. privacy, trust)
  - Technology (e.g. apps, wearable technology)
  - Real-world, health data sharing initiatives
- The topics detailed on the subsequent pages were suggested at our December workshop
- We asked respondents to choose the top three proposed topic in each area that were most important/of greatest interest, in their opinion
- Respondents were advised that the most popular topics across all respondents will be prioritised and covered earlier in the year
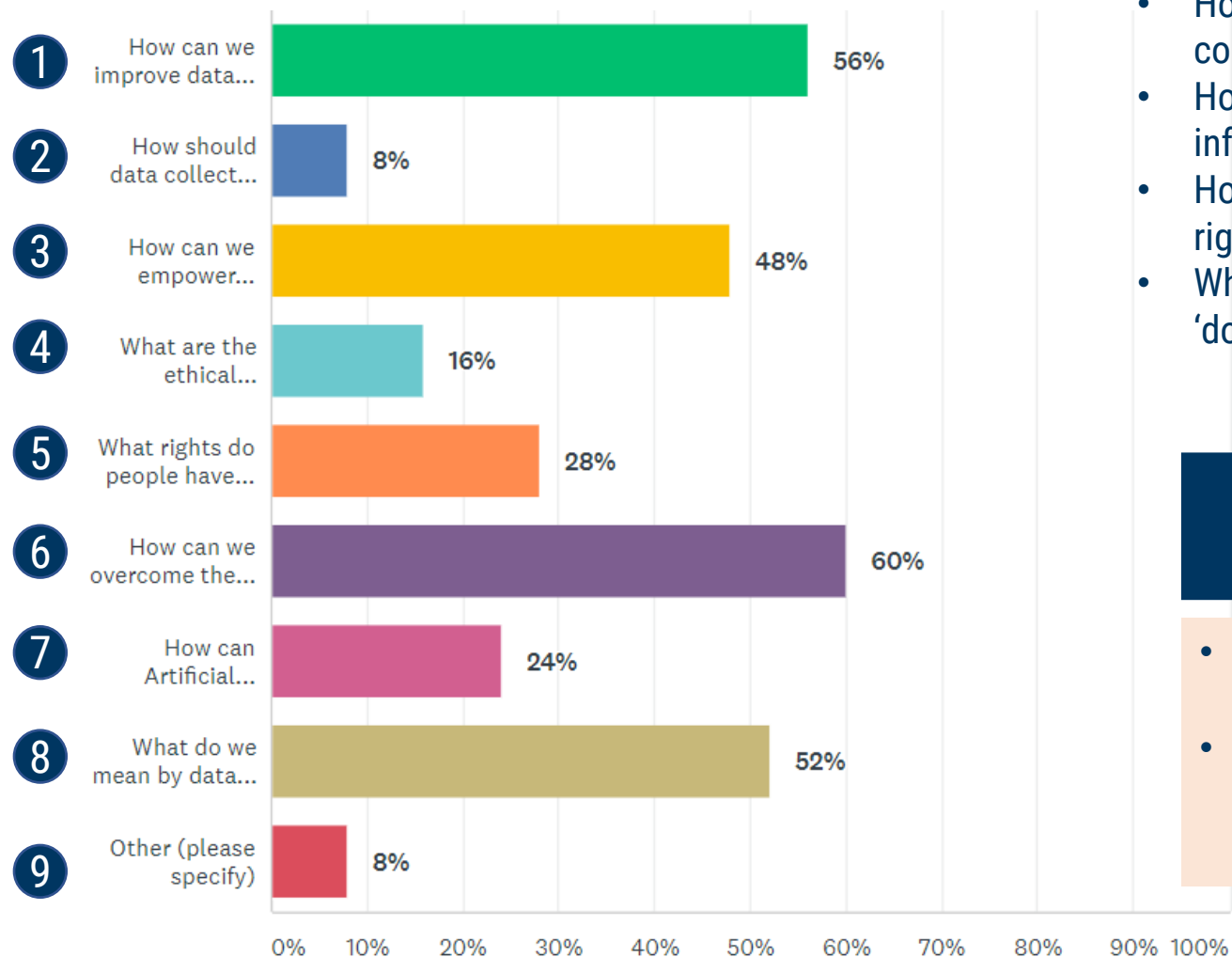
#DataSavesLives

Proposed topics: ethics

1. How can we improve data literacy among patient communities?
2. How should data collection be approached among those who cannot give consent (e.g. people with dementia or children)?
3. How can we empower patients and caregivers to request information about their own health data?
4. What are the ethical concerns surrounding the use of Artificial Intelligence (AI) and predictive technologies, in particular?
5. What rights do people have concerning the use of their data?
6. How can we overcome the tension between individual privacy rights and the wider societal good of health data use?
7. How can Artificial Intelligence (AI) be biased and what can be done to address this?
8. What do we mean by data altruism? Should patients be able to 'donate' their data for societal benefit?
9. Other (respondent to specify)

#DataSavesLives

Survey results: ethics

#	Topic	Percentage
1	How can we improve data...	56%
2	How should data collect...	8%
3	How can we empower...	48%
4	What are the ethical...	16%
5	What rights do people have...	28%
6	How can we overcome the...	60%
7	How can Artificial...	24%
8	What do we mean by data...	52%
9	Other (please specify)	8%

PRIORITY TOPICS

- How can we improve data literacy among patient communities?
- How can we empower patients and caregivers to request information about their own health data?
- How can we overcome the tension between individual privacy rights and the wider societal good of health data use?
- What do we mean by data altruism? Should patients be able to 'donate' their data for societal benefit?

Other

- How can we connect existing data registries without duplication, ethical and safety concerns?
- The role of data in our recovery and rebuild following COVID-19
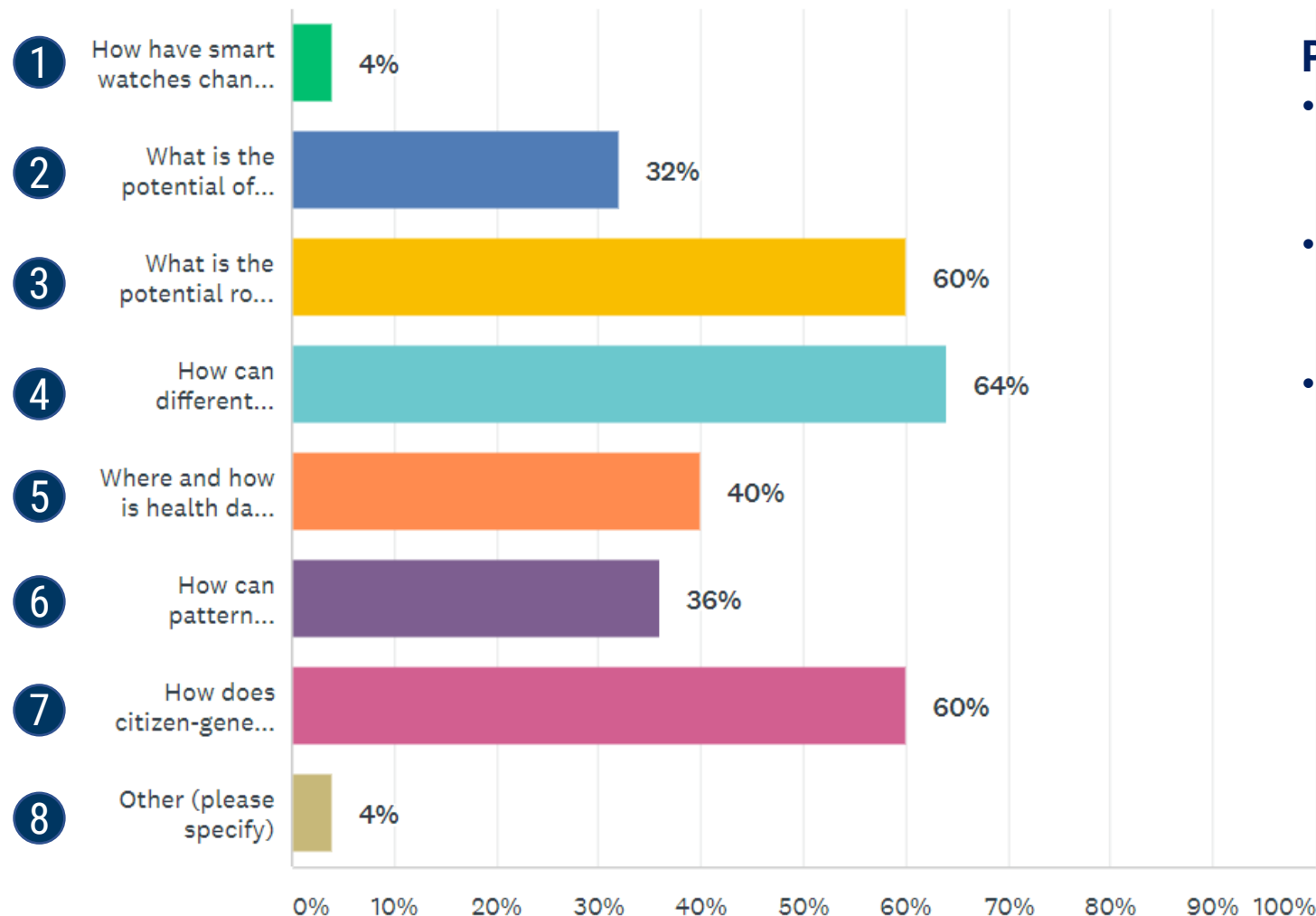
#DataSavesLives

Proposed topics: technology

1. How have smart watches changed the way citizens create and consume health data?

2. What is the potential of wearable technology for remote health monitoring? Looking to the future of digital health data tracking

3. What is the potential role of Artificial Intelligence (AI) in disease management and patient support?

4. How can different sources of health data speak to each other? E.g. different registries, smartphone or wearable data?

5. Where and how is health data collected?

6. How can pattern recognition technology support rapid diagnosis and improve access to care?

7. How does citizen-generated health data compare to healthcare professional-generated health data?

8. Other (respondent to specify)

#DataSavesLives

Survey results: technology

#	Topic	%
1	How have smart watches chan...	4%
2	What is the potential of...	32%
3	What is the potential ro...	60%
4	How can different...	64%
5	Where and how is health da...	40%
6	How can pattern...	36%
7	How does citizen-gene...	60%
8	Other (please specify)	4%

PRIORITY TOPICS:
- What is the potential role of Artificial Intelligence (AI) in disease management and patient support?
- How can different sources of health data speak to each other? E.g. different registries, smartphone or wearable data?
- How does citizen-generated health data compare to healthcare professional-generated health data?

Other

- How can we integrate diverse sources of data across platforms?

#DataSavesLives

Proposed topics: real-world initiatives

1. The use of ambient intelligence and ambient data to inform health measures (e.g. weather, pollution, traffic)

2. The use of patient-reported outcomes (PROs) in clinical research to inform the development of more meaningful health interventions

3. How patient groups have successfully overcome capacity and financial barriers to run successful community health data initiatives

4. How patient groups have benefited from leading or collaborating on health data initiatives

5. Spotlight on the successful public-private collaborations

6. Spotlight on successful patient data/self-management apps

7. How caregivers have been successfully involved in a health data sharing initiative

8. Other (respondent to specify)

#DataSavesLives

Survey results: real-world initiatives

#	Label	Value
1	The use of ambient...	12%
2	The use of patient-repo...	76%
3	How patient groups have...	32%
4	How patient groups have...	64%
5	Spotlight on the successf...	28%
6	Spotlight on successful...	48%
7	How caregivers have been...	40%
8	Other (please specify)	
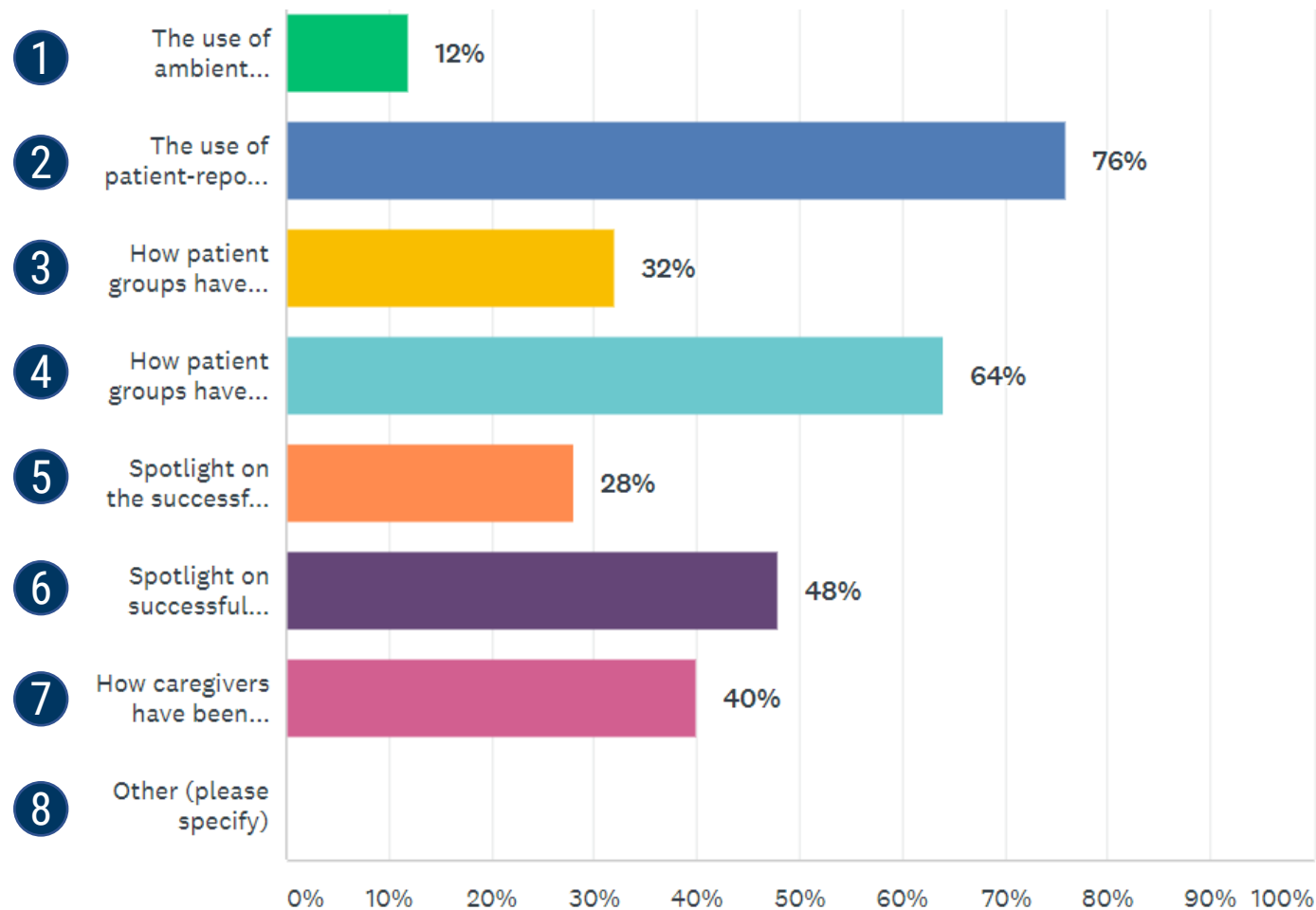
PRIORITY TOPICS:
- The use of patient-reported outcomes (PROs) in clinical research to inform the development of more meaningful health interventions
- How patient groups have benefited from leading or collaborating on health data initiatives
- Spotlight on successful patient data/self-management apps

#DataSavesLives

Priority topics to be addressed in 2021

Ethics

- How can we improve data literacy among patient communities?
- How can we empower patients and caregivers to request information about their own health data?
- How can we overcome the tension between individual privacy rights and the wider societal good of health data use?
- What do we mean by data altruism? Should patients be able to 'donate' their data for societal benefit?

Technology

- What is the potential role of Artificial Intelligence (AI) in disease management and patient support?
- How can different sources of health data speak to each other? E.g. different registries, smartphone or wearable data?
- How does citizen-generated health data compare to healthcare professional-generated health data?
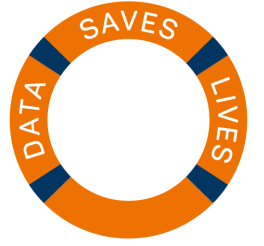
Real-world initiatives

- The use of patient-reported outcomes (PROs) in clinical research to inform the development of more meaningful health interventions
- How patient groups have benefited from leading or collaborating on health data initiatives
- Spotlight on successful patient data/self-management apps

#DataSavesLives

Priority tools for our patient-group toolkit

Patient-group toolkit

- Our patient-group focused toolkit aims to support patient groups (primarily) with the information, guidance and templates needed to communicate about health data successfully and launch their own health data initiatives

- The guidance tools detailed on the subsequent pages were suggested at our December workshop

- We asked respondents to choose the top three proposed tools in each area that were most important/of greatest interest, in their opinion

- Respondents were advised that the most popular tools across all respondents will be prioritised for the first iteration of the toolkit to be launched by summer 2021
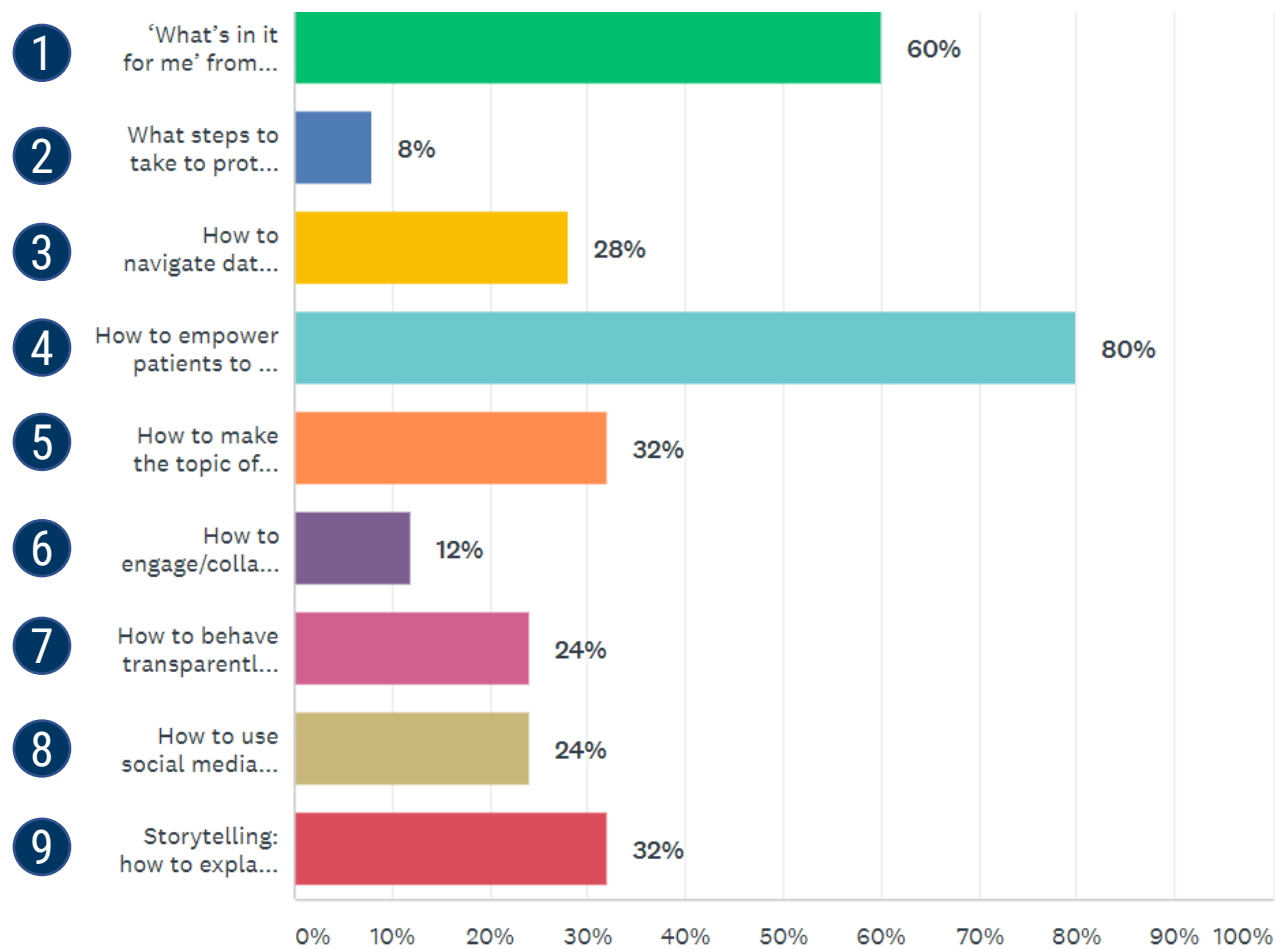
#DataSavesLives

Proposed guidance

1. 'What's in it for me' from a patient group perspective and from a patient influencer (individual advocate) perspective

2. What steps to take to protect health data

3. How to navigate data privacy laws in Europe

4. How to empower patients to use digital health and share data

5. How to make the topic of health data engaging and user-friendly

6. How to engage/collaborate with healthcare professionals

7. How to behave transparently when it comes to health data collection and use

8. How to use social media to raise awareness of health data sharing

9. Storytelling: how to explain how data saves lives

#DataSavesLives

Survey results: guidance

PRIORITY GUIDANCE:
- 'What's in it for me' from a patient group perspective and from a patient influencer (individual advocate) perspective
- How to empower patients to use digital health and share data
- How to make the topic of health data engaging and user-friendly
- Storytelling: how to explain how data saves lives
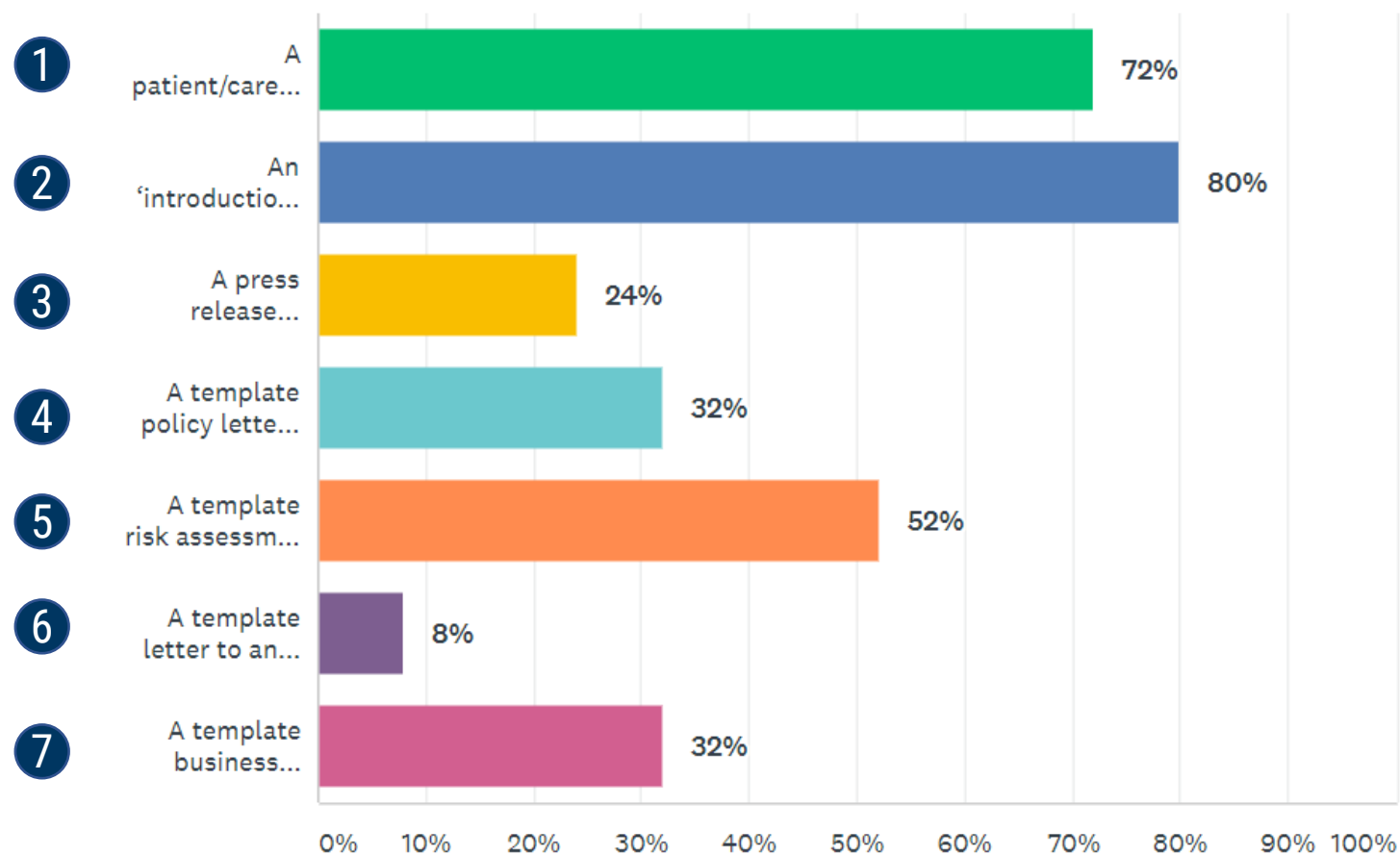
#DataSavesLives
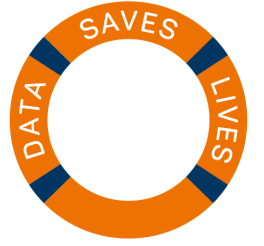
Proposed templates

1. A patient/caregiver survey template to understand their views regarding health data sharing

2. An 'introduction to health data' workshop/webinar agenda template with the aim to provide patients and caregivers with a basic knowledge of the key themes

3. A press release template to announce the launch of/results from a health data initiative

4. A template policy letter, inviting political organisations to support or advocate for a health data initiative

5. A template risk assessment to help patient groups to decide which health data initiatives to get involved with (e.g. if asked to support a public/private enterprise)

6. A template letter to an academic institute to request support or involvement in a health data initiative

7. A template business plan/proposal for a health data sharing initiative to help secure funding

#DataSavesLives

Survey results: templates

PRIORITY TEMPLATES:
- A patient/caregiver survey template to understand their views regarding health data sharing
- An 'introduction to health data' workshop/webinar agenda template with the aim to provide patients and caregivers with a basic knowledge of the key themes
- A template risk assessment to help patient groups to decide which health data initiatives to get involved with (e.g. if asked to support a public/private enterprise)
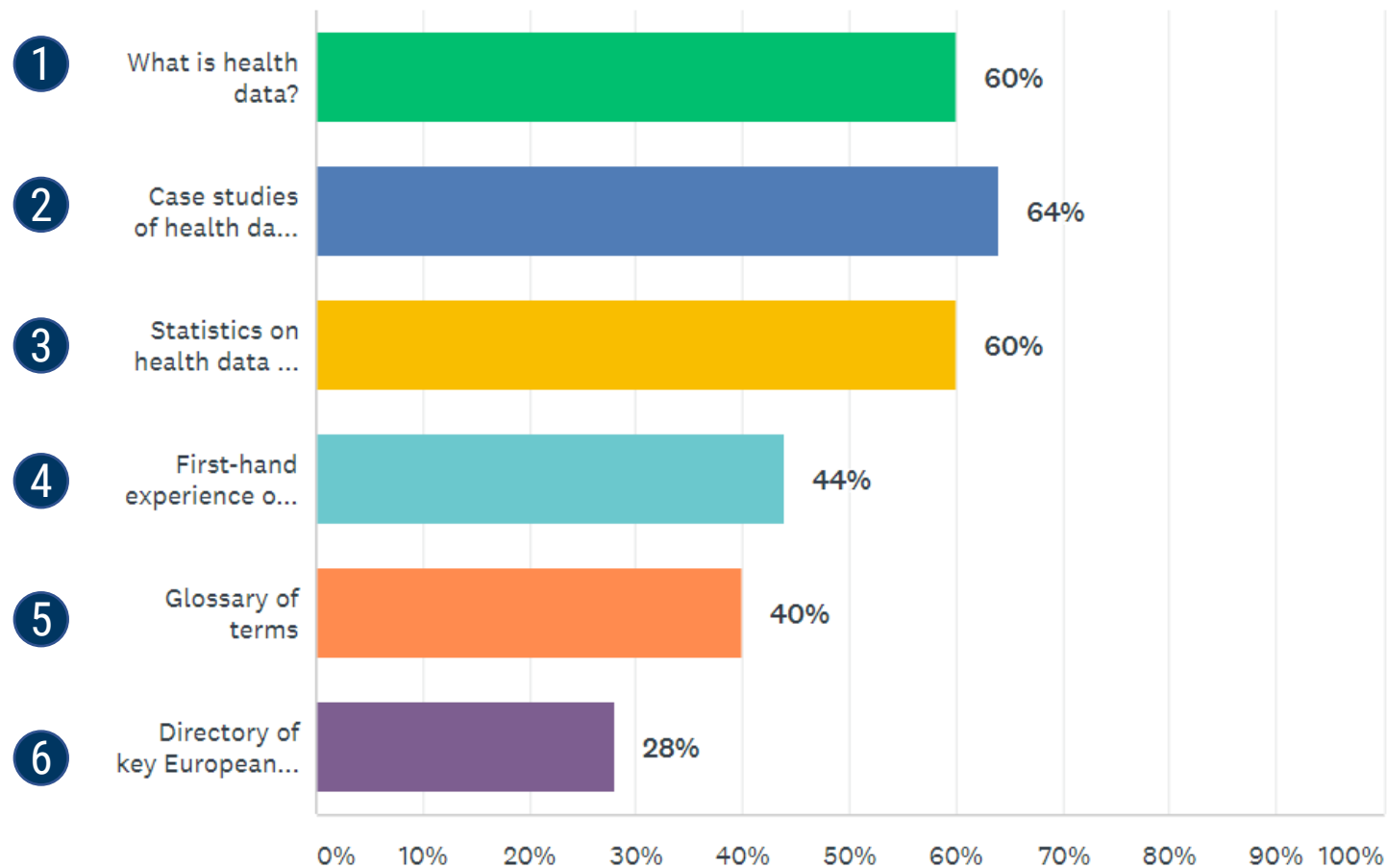
#DataSavesLives
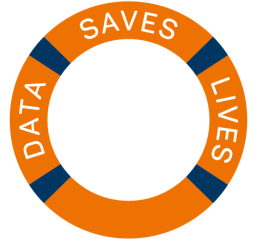
Proposed information sheets

1. What is health data?

2. Case studies of health data initiatives

3. Statistics on health data use across Europe

4. First-hand experience of data sharing from the research participant perspective

5. Glossary of terms

6. Directory of key European organisations and companies involved in safeguarding and advocating for responsible health data sharing

#DataSavesLives

Survey results: information sheets

1	What is health data?	60%
2	Case studies of health da...	64%
3	Statistics on health data ...	60%
4	First-hand experience o...	44%
5	Glossary of terms	40%
6	Directory of key European...	28%

PRIORITY INFORMATION SHEETS:
- What is health data?
- Case studies of health data initiatives
- Statistics on health data use across Europe

#DataSavesLives

Priority tools to be included in first toolkit

Guidance

- 'What's in it for me' from a patient group perspective and from a patient influencer (individual advocate) perspective
- How to empower patients to use digital health and share data
- How to make the topic of health data engaging and user-friendly
- Storytelling: how to explain how data saves lives

Templates

- A patient/caregiver survey template to understand their views regarding health data sharing
- An 'introduction to health data' workshop/webinar agenda template with the aim to provide patients and caregivers with a basic knowledge of the key themes
- A template risk assessment to help patient groups to decide which health data initiatives to get involved with (e.g. if asked to support a public/private enterprise)

Information sheets

- What is health data?
- Case studies of health data initiatives
- Statistics on health data use across Europe

#DataSavesLives

Next steps

Next steps

- Many thanks to those of you who said you were happy to contribute to our editorial, we will be in touch to discuss your involvement further

- The editorial and event calendars on the following pages provide an overview of the topics to be featured in order of priority based on the survey results

- These calendars are intended as a guide only

- Connect with and follow us at:

  📒 datasaveslives.eu/

  🐦 twitter.com/DataSaves_Lives

  📷 instagram.com/datasaves_lives/

  📘 https://www.facebook.com/DSL.DataSavesLives

  ✉ dsl-info@eu-patient.eu

#DataSavesLives

Editorial calendar based on results

JAN	FEB	MAR	APR	MAY	JUN
Blog: What is the potential role of Artificial Intelligence (AI) in disease management and patient support? *- Member of MedTech Europe*	**Blog:** What do we mean by data altruism? Should patients be able to 'donate' their data for societal benefit? *(TBC)*	**Blog:** How can we empower patients and caregivers to request information about their own health data? *(TBC)*	**Blog:** How does citizen-generated health data compare to healthcare professional-generated health data? *(TBC)*	**Blog:** The role of data in our recovery and rebuild following COVID-19 *(TBC)*	**Blog:** What is the potential of wearable technology for remote health monitoring? Looking to the future of digital health data tracking *(TBC)*

JUL	AUG	SEP	OCT	NOV	DEC
Blog: How caregivers have been successfully involved in a health data sharing initiative *(TBC)*	**Blog:** Where and how is health data collected? *(TBC)*	**Blog:** How can pattern recognition technology support rapid diagnosis and improve access to care? *(TBC)*	**Blog:** What rights do people have concerning the use of their data? *(TBC)*	**Blog:** Spotlight on the successful public-private collaborations *(TBC)*	**Blog:** What are the ethical concerns surrounding the use of AI and predictive technologies, in particular? *(TBC)*

#DataSavesLives

Event calendar based on results

JAN	FEB	MAR	APR	MAY	JUN
	Tweet Chat: How can we improve data literacy among patient communities?	**Webinar:** The use of PROs in clinical research to inform the development of more meaningful health interventions		**Tweet Chat:** How can we overcome the tension between individual privacy rights and the wider societal good of health data use?	**Webinar:** How patient groups have benefited from leading or collaborating on health data initiatives

JUL	AUG	SEP	OCT	NOV	DEC
Tweet Chat: Spotlight on successful patient data/self-management apps		**Webinar:** How can different sources of health data speak to each other? E.g. different registries, smartphone or wearable data?	**Tweet Chat:** How patient groups have successfully overcome capacity and financial barriers to run successful community health data initiatives	**Webinar:** The use of ambient intelligence and ambient data to inform health measures (e.g. weather, pollution, traffic)	

#DataSavesLives