DATA SAVES LIVES **TEMPLATE SURVEY** TO UNDERSTAND PATIENT AND CARER CONFIDENCE IN HEALTH DATA-SHARING

As a starting point to help you better understand the knowledge and beliefs around health data sharing of your community, **Data Saves Lives** has developed this easily adaptable survey template that you can tailor to suit your needs.

Online survey platforms, such as SurveyMonkey® and Google Forms®, provide a secure and accessible way of surveying your members or network and are intuitive to set up. These platforms can be accessed by non-paying account holders and allow users to upload and share surveys, with a limit of 10 free questions on SurveyMonkey®. They also both provide supplementary analytics and statistics of the results after the survey has been completed and are an extremely useful tool for patient groups or individuals with limited resources.

We recommend if you share a survey like this with your members or network, that you include a description of what electronic health data is as an introduction, to provide context. You can use the description from the introductory section to this toolkit.

Example survey questions *begin on the next page…*

Example survey questions

1. On a scale from 1–5, to what extent do you agree with the statements below?
(**1** = completely disagree, **3** = neither disagree nor agree, **5** = completely agree)

☐ I feel comfortable sharing my health data if I know it is contributing towards wider-societal benefit

☐ I feel confident that there are safeguards in place that will protect my health data and ensure that it is not exploited for commercial gain

☐ I understand what happens to my health data once it has been shared and who controls it

☐ I feel confident that by sharing my health data, my information will make a positive impact in the field of medical research and clinical trials

☐ By donating my health data, I feel confident that my privacy and anonymity (should I choose to remain anonymous) is protected

☐ I understand what my given consent implies when I agree to provide health data and the 'limitations' of this consent, such as in instances where I should choose to withdraw it

☐ I believe that by donating my health data, I may suffer adverse consequences as a result e.g. it could affect my health insurance, or my employment options

☐ I fully trust that healthcare regulatory bodies and corporations will use my data to benefit society at large

☐ I am concerned about sharing my personal health data (and those separate from my condition(s) – such as age, ethnicity & sexual orientation) in case it is made publicly accessible

2. Which individuals or organisations do you feel most comfortable sharing your health data with? Tick all that apply

☐ My healthcare team   ☐ Mobile phone apps

☐ Hospitals   ☐ Digital health tools

☐ Universities   ☐ Online forums

☐ Drug companies   ☐ Social media platforms

☐ Charities   ☐ Medical devices

☐ Patient groups   ☐ Other [Open text]

3. Which individuals or organisations do you feel least comfortable sharing your health data with? Tick all that apply

☐ My healthcare team

☐ Hospitals

☐ Universities

☐ Drug companies

☐ Charities

☐ Patient groups

☐ Mobile phone apps

☐ Digital health tools

☐ Online forums

☐ Social media platforms

☐ Medical devices

☐ Other [Open text]

4. Please explain your responses to questions 3 & 4. [Open text]

5. What concerns might you have regarding your health data use? [Open text]

6. In your opinion, what could patient groups and data collectors do to address these concerns and increase your trust in health data-sharing initiatives? [Open text]

7. If you are interested in learning more about health data, which methods of communication would you find most helpful from us? Tick all that apply

☐ An online webinar

☐ A discussion session at our annual meeting

☐ A factsheet

☐ More information on our website

☐ Regular updates on research initiatives

8. Please confirm if you are:

☐ A patient

☐ A carer

☐ Other [Open text]

☐ Prefer not to say