asthma UK

Data sharing and technology:

Exploring the attitudes of people with asthma

Contents

This report was written by Brigitte West and Andrew Cumella from Asthma UK.

We'd like to thank the people with asthma who took the time to answer this survey.

Foreword

Every day we see news stories highlighting how data can be used to improve health. These span a huge range; using data to better personalise treatments, highlighting where care most needs to improve, or employing artificial intelligence to assist healthcare professionals in diagnosis. Opportunities also exist for patient data to be used to improve asthma services and advance asthma research. However, we cannot ignore that the way data is collected, shared and used is prompting new and complex policy, legal and ethical questions.

Asthma UK recognises that we are still in the very early stages of establishing common practice and societal consensus on the role of personal data in delivering core services. Health is the arena where decisions about what is right or morally acceptable are often played out. Health data looms large in any discussions about data privacy and security, with understandable concerns around how sharing personal health data might impact how people are treated by insurers, employers or even friends and family. As the use of personal data becomes increasingly enshrined in processes, systems and ways of working, we must ensure ethical standards and clarity about the obligations of citizens and organisations keep pace. The National Council of Voluntary Organisations (NCVO) recently called for charities to take a leadership role in this space.

NCVO said: "It's clear that there are social, ethical and legal questions arising from technology, and charities will need to be ready and able to make the case for what they think is right."[1]

Asthma UK endorses this call to action. We believe that for the huge potential of health data to be realised the public voice must be prominent in shaping new societal norms. For the last three years we have been exploring emerging attitudes to new data and technology from people with asthma, using this to actively contribute to developing policy at a national level. Underpinning this has been leading a workstream to understand attitudes of health care professionals and people with asthma to new data driven healthcare as part of the European MyAirCoach consortium[2]. More recently we explored usage of new digital consumer health and NHS services as part of our 2017 Annual Asthma Survey[3], in recognition this is one of the most dramatic changes to service delivery we have seen in the NHS.

However, in 2018 we wanted to do more. This year, we have the introduction of EU General Data Protection Regulation, NHS National Data Opt Out and ever more active public debate fuelled by data breach revelations in the media every week. We wanted a more up to date understanding of how people with asthma view the increasing use of personal data to drive core services, and where their limits might be.

"I hope I get to use something involving technology and tracking my asthma soon, it would transform my life"

Person with asthma

This report summarises our findings from a survey of over 3000 people with asthma taken in early 2018. Our aim is to contribute to the emerging consensus, and offer reassurance that there is support for data driven healthcare among people with asthma, albeit with important watch-outs.

People with asthma comprise 1 in 11 of the population[4] and account for 2-3% of GP consultations per year[5]. The annual cost of asthma to the UK is estimated at £1.1 billion[6]. This survey demonstrates the appetite from people with asthma to engage in the debate and help shape the future of asthma care. Getting it right is not only good for this group, but will have significant impact on the healthcare system.

Within a rapidly evolving landscape, we are realistic that we will need to keep engaging and understanding the views of people with asthma. New technology will continually challenge us with new ethical questions. It is important that these are addressed from an evidenced point of view, with the voice of the most important people in the healthcare system, the patient, central to any decisions.

Done badly we could see progress stall, with public trust eroded and data fragmented across silos. We hope helping to facilitate continual, informed public debate on the issues around data will help us to deliver on the promise of data driven healthcare efficiently, effectively to improve the lives of people affected by asthma.

Kay Boycott
Chief Executive

Summary of key findings:

Health data sharing scenarios

83% of people with asthma are comfortable with their confidential health data being shared for research to develop new asthma treatments

88% of people with asthma would be willing for their confidential health data to be used for service improvement

94% of people with asthma would be willing for their anonymised health data to be shared with an analytics company to develop a tool to target people particularly at risk of an asthma attack

Data from new technology to improve asthma care

93% of people with asthma would welcome the use of data collected through apps to tell healthcare professionals when their asthma needs to be reviewed

88% of people with asthma would be happy to use a smart inhaler if they were available on the NHS

Introduction

DATA SHARING CAN PREVENT ASTHMA ATTACKS AND SAVE LIVES

Asthma is a common condition – 1 in 11 people in the UK[4] – that affects people of all ages with varying degrees of severity across their lifetimes. The majority of asthma care takes place in primary care, but asthma attacks often require A&E or hospital admission. There have been a number of high profile asthma deaths that have been directly attributed to a lack of data sharing between healthcare services[7] that has resulted in risk factors for a life-threatening asthma attack not being identified and acted upon. The National Review of Asthma Deaths in 2014 concluded that two thirds of asthma deaths would be preventable by better management[8].

Ensuring that health care professionals have access to complete information and are provided with tools that allow them to easily analyse data in real time to identify those at risk, will stop preventable asthma deaths from happening. Whilst progress is being made to digitise the NHS and improve data sharing, key technical barriers remain, including the lack of interoperability of NHS IT systems and security issues with old systems. However, there are areas that demonstrate barriers can be overcome and data can be used effectively to drive improvements in asthma care.

Case study:
Whole Systems Integrated care Programme

The Whole Systems Integrated Care Programme in North-West London has linked patient data across 8 CCGs, including hospitals, GP practices, community and mental health trusts and adult social care, to allow integrated care through a shared dashboard. An asthma dashboard has been developed that quickly provides a view of key risk indicators and classifies asthma risk into "red flag" status to help clinicians quickly identify people with asthma that are at high risk. This can be used to allow patients to be prioritised for review and resources to be targeted to those in most need. A printout of risk factors can also be provided to patients to help them understand their asthma better. The asthma dashboard is currently being used in all 8 of the CCGs participating in the programme[9].

Technology has the potential to play a critical role

Asthma is a complex, episodic condition and technology provides an opportunity to build up a more complete picture of someone's asthma. There is potential for this data, combined with other data

(e.g. clinical, environmental), to be used to predict asthma attacks, aid clinical decision making and drive better targeting of healthcare resources. There is also the potential to transform how people manage their own asthma, allowing them to easily take into account different streams of external information (e.g. pollen count, pollution levels) and helping them to make adjustments to their treatments, health interactions and lives.

We also know that many of those at higher than average risk of an asthma attack are high users of technology[10]. We believe that technologies such as health apps, wearables and connected devices (e.g. smart inhalers) have the potential to transform how their asthma is managed and monitored[11].

Smart inhalers – a promising technology

As passive data collection (e.g. data collected by a device without the individual having to enter information) is key for asthma technology to be widely adopted, smart inhalers have been heralded as a particularly promising technology to drive technology enabled transformation asthma management[12]. Smart inhalers are able to passively monitor inhaler usage and adherence to treatment and this precision data could be used to help to identify those at high risk of a life-threatening asthma attack.

Data to drive research and innovation

The data held in clinical records and provided by new technologies also offers an exciting opportunity to drive asthma research and help develop new insight into asthma, ultimately leading to better treatments, improved services and outcomes for people with asthma.

Balancing the risks and benefits

The use of patient data is not without risks. Data needs to have strong governance surrounding it, with controlled access and robust IT systems to keep data safe and secure. It is vital that patient privacy is protected, consent upheld and sufficient safeguards are in place to reduce the risk of cyberattacks and data breaches. In research conducted by the Open Data Institute (ODI), 94% said trust was important in deciding to share personal data[13]. New legislation is an important step in building that trust, along with an honest dialogue about risk between clinicians, researchers and patients[14].

Given the rapid pace of technical innovation, it is key to ensure that there are policies and guidelines in place to protect people with asthma and ensure that they know how these technologies will store, use and share data.

WHY WE COMMISSIONED THIS REPORT

In this context, Asthma UK conducted a survey designed to gain insight into people with asthma's attitudes to the sharing of personal health data for research and service improvement, alongside their views on the use of new technology and data in their asthma care. This report presents an overview of our findings and recommended next steps.

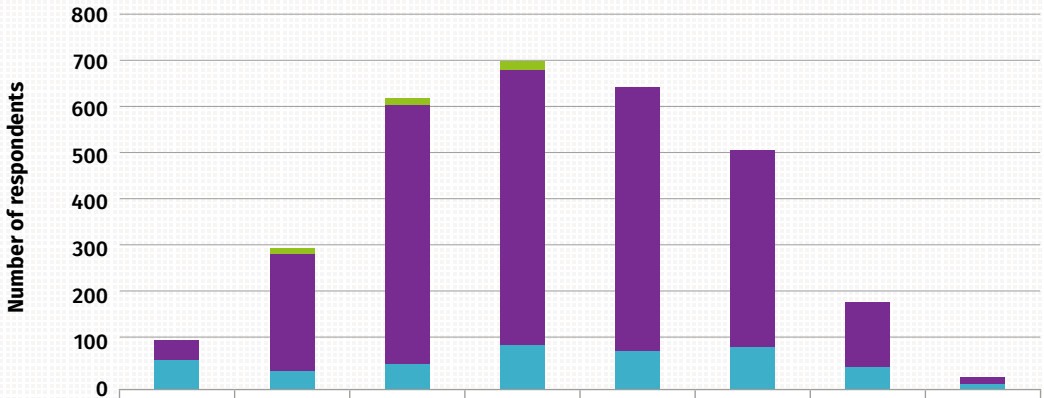
Our methodology

The survey asked respondents their opinion on a range of scenarios relating to the use of their health data and was conducted online and ran from mid-February to mid-March 2018. It was promoted in Asthma UK's regular newsletter, on social media and via the Asthma UK website. The majority of survey respondents were acquired via paid social media (2,114 completions from paid social on Facebook). A full list of the survey questions can be found in Appendix B.

The survey had 3054 responses in total. Of these responses, 2356 were from England, 134 from Northern Ireland, 381 from Scotland and 183 from Wales. Women made up most of the survey respondents (84.6%). Considering that the gender balance in asthma prevalence is 56% women and 44% men, women were overrepresented in this survey.[4] The most well represented age groups were 30-39 (20.1% of respondents), 40-49 (22.8%) and 50-59 (21.1%). Interestingly, there were no significant variations in any of the question responses across the different age groups.

It is important that the debate around the sharing of personal health data is shaped by a representative sample of the general public; encouraging more men and the younger and older ends of the age spectrum to participate in future insight work and public debates on this topic is something to target. A full breakdown of survey responses to each of the questions by age can be found in Appendix A.

Figure 1: Survey respondents by age and gender



	17 or under	18-29	30-39	40-49	50-59	60-69	70-79	80+
Women	45	256	561	599	562	417	136	8
Men	55	38	52	94	83	91	44	6
Other	0	4	1	2	0	0	0	0

Age group

Health data sharing scenarios

In our survey, we asked three scenario-based questions to gain insight on people with asthma's views on the use of personal health data for the following purposes:

- ***Confidential patient data* sharing for research to develop new asthma treatments**
- ***Confidential patient data* sharing to improve asthma services**
- ***Anonymised patient data* sharing for research to develop a tool to target people particularly at risk of an asthma attack**

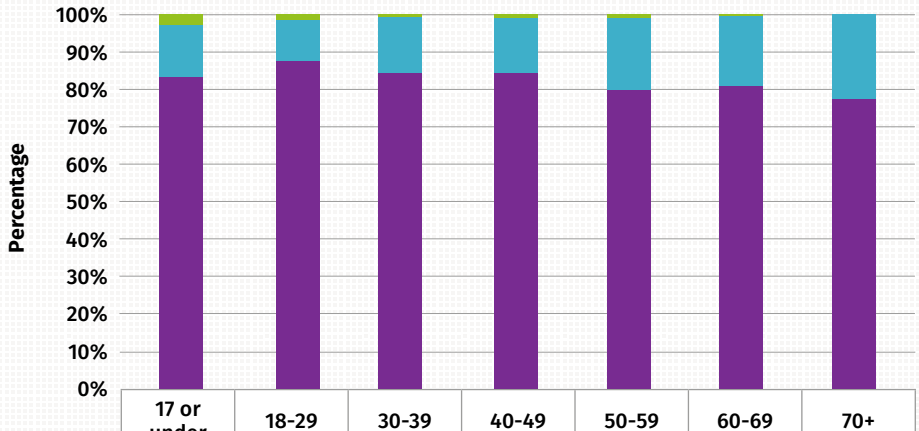
Respondents reacted positively to the use of their health data in all three scenarios listed. 93.7% (2207 of 2356 respondents) were comfortable with their anonymised data being used to develop a tool to target treatment to those most at risk of an asthma attack. This was the question with the most positive response, although the other two questions also saw large positive majorities, with 82.7% comfortable with their confidential patient data being used for research and 87.9% comfortable with their confidential patient data being used for service improvement.

The three scenarios presented are possible real-world uses of health data in an asthma context and were only asked to respondents in England. The first two scenarios were asked to inform knowledge ahead of the introduction of the National Data Opt-Out in May 2018[15]. It should be noted that in each scenario, the type of organisation handling the data (e.g. academic institution) and the reason the data was needed (e.g. to develop new asthma treatments) was clearly communicated, so this cannot be extrapolated to other scenarios. The full wording of each scenario and our definition of confidential patient information and anonymised patient information is available in Appendix B. A full breakdown of the responses is available in Appendix A.

Data sharing for research to develop new asthma treatments

When asked about sharing their their confidential health data for researching new asthma treatments, in total 82.7% of people with asthma would do so. This is marginally higher than the general public's attitude to sharing their anonymised medical records for research (where 77% would be willing)[16]. When the survey results are broken down by age, at least

Figure 2: Data sharing for research to develop new asthma treatments - *How comfortable would you be with your data being used in this way?*



	17 or under	18-29	30-39	40-49	50-59	60-69	70+
Very comfortable or comfortable	83.8%	87.4%	84.8%	84.4%	79.7%	81.0%	77.4%
Very uncomfortable or uncomfortable	13.5%	11.3%	14.5%	15.0%	19.5%	18.8%	22.0%
I do not understand the question	2.7%	1.4%	0.7%	0.6%	0.8%	0.2%	0.1%

Age group

three quarters of each age group were either 'very comfortable' or 'comfortable' with their health data being shared for research purposes. The most enthusiastic group was those aged 18-29, with 87.4% happy sharing their data.

Data sharing to improve asthma services

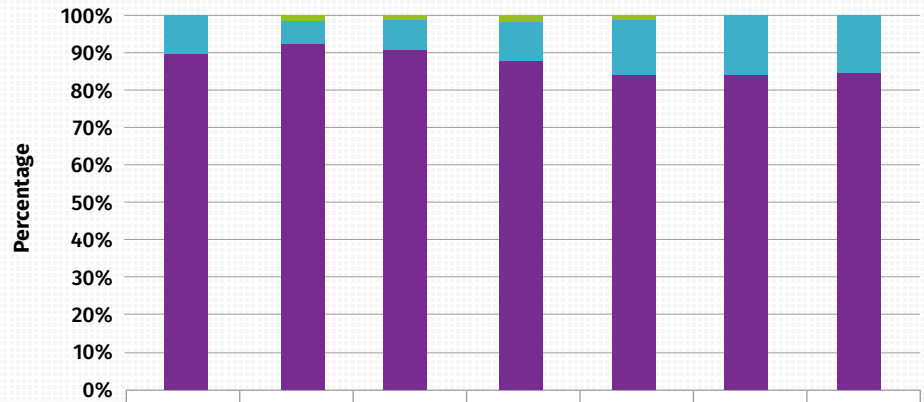
In terms of sharing their confidential health data for service improvement initiatives, younger age groups were slightly more enthusiastic about their health data being used for this function, with the percentage being comfortable with their data being shared ranging from 93.2% for ages 18-29 to 84.3% for ages 60-69.

Data sharing for research to develop a tool to target people particularly at risk of an asthma attack

Interestingly, over 90% of every age group were comfortable with their anonymised data being shared in the scenario of the NHS working alongside a data analytics company to develop a new tool to identify the people with asthma at risk of having an asthma attack and target treatment. Whilst this is a very specific scenario, the response indicates that people with asthma would support the NHS working with commercial companies if there is a benefit for them. Previous public attitudes research found that only 53% of people would be happy for their data to be used by commercial organisations if it was for research[17], suggesting people with asthma could be more accepting of commercial access than the general public, or that the partnership with the NHS is key. However, commercial relationships to data are complex and the level of benefit to people with asthma will vary, so more research is needed to fully understand people's views on this.

Upon further analysis, the age group with the most "very comfortable" responses was the 18-29 age group (55%, 122 of 222) and the proportion of "very comfortable" responses slightly declined with age. The group with the lowest proportion of "very comfortable" was 70+ age group (39%, 62 of 159).

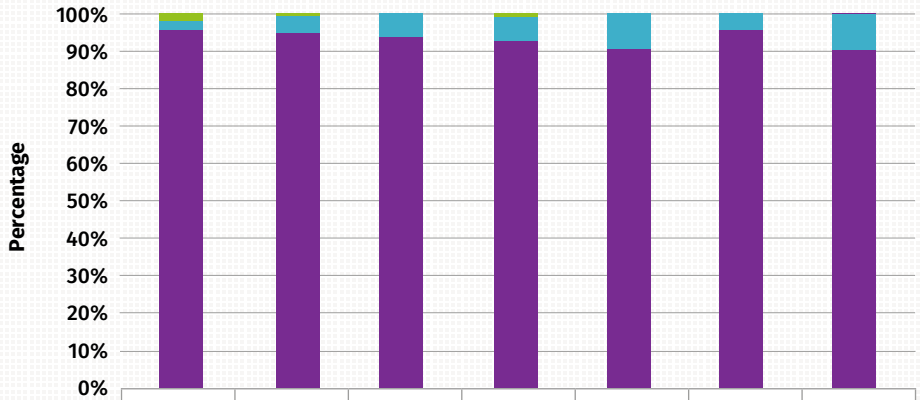
Figure 3: Data sharing to improve asthma services - *How comfortable would you be with your data being used in this way?*



	17 or under	18-29	30-39	40-49	50-59	60-69	70+
Very comfortable or comfortable	90.5%	93.2%	91.9%	88.9%	84.6%	84.3%	84.9%
Very uncomfortable or uncomfortable	9.5%	6.3%	7.9%	10.1%	15.2%	15.7%	15.1%
I do not understand the question	0.0%	0.5%	0.2%	0.9%	0.2%	0.0%	0.0%

Age group

Figure 4: Data sharing with analytics company for research to develop a tool to target people particularly at risk of an asthma attack - *How comfortable would you be with your data being used in this way?*



	17 or under	18-29	30-39	40-49	50-59	60-69	70+
Very comfortable or comfortable	95.9%	95.5%	94.1%	93.4%	91.3%	96.0%	91.2%
Very uncomfortable or uncomfortable	2.7%	4.1%	5.9%	6.2%	8.7%	4.0%	8.8%
I do not understand the question	1.4%	0.5%	0.0%	0.4%	0.0%	0.0%	0.0%

Age group

Key insights

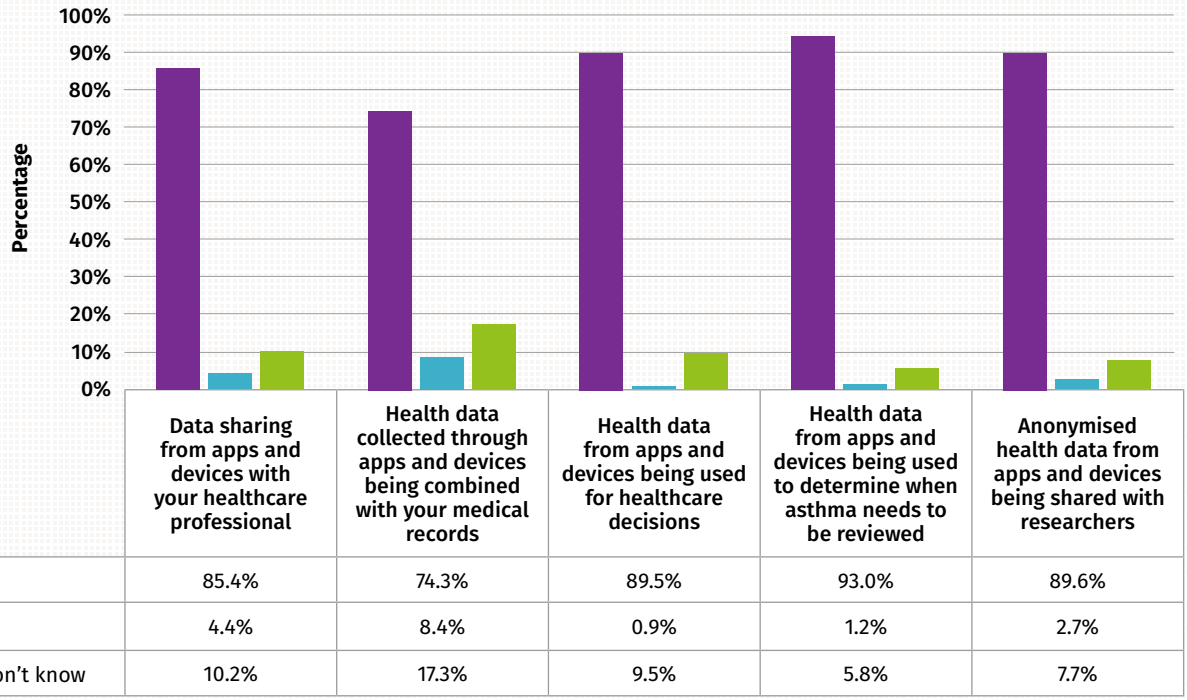
- The results from the three scenario-based questions indicate that if people with asthma understand who is accessing their data, why their data was needed and the public benefit, they are happy to share their data for research and service planning.
- More research is needed to fully understand and define the value perceived from the use of patient data in each scenario and the variations in opinion depending on different demographics, such as age.
- These results echo the findings of a systematic review on public attitudes on the use of medical data for research, which found a widespread willingness to share health data, although this support was not unconditional and people had generalised concerns around the motivation for access data and the competence of the research organisation in data handling[18].

Data from new technology to improve asthma care

"I am very nervous about seeking medical help... I think I would really benefit from medically designed software that could make that decision for me"

Person with asthma

Figure 5: Health data being collected via an app or other new technology and being used for different purposes - *How comfortable would you be with your data being used in this way?*



	Data sharing from apps and devices with your healthcare professional	Health data collected through apps and devices being combined with your medical records	Health data from apps and devices being used for healthcare decisions	Health data from apps and devices being used to determine when asthma needs to be reviewed	Anonymised health data from apps and devices being shared with researchers
Yes	85.4%	74.3%	89.5%	93.0%	89.6%
No	4.4%	8.4%	0.9%	1.2%	2.7%
I don't know	10.2%	17.3%	9.5%	5.8%	7.7%

The results shown in Figure 5 indicate the majority of people with asthma were positive about the potential use of data collected through new technologies.

There were no significant variations in any of these question responses across the different age groups (a full breakdown of each question by age can be found in Appendix A). The most positive response (93.0%, 2464 of 2649) was on the use of data collected through apps and devices being used to tell healthcare professionals (HCPs) when an asthma review is needed. This aligns with previous research on people with asthma's perspectives on mHealth that demonstrated that the most popular potential uses for mHealth were to monitor asthma over time (72%) and to collect data to present to healthcare teams (70%).[2] The question that most people had reservations about concerned health data collected through apps being combined with their medical record. This question had the highest proportion answering 'I don't know' (17.3%, 506 of 2919), which could suggest that it is something people with asthma could be more enthusiastic about if it was communicated appropriately, but we would need to explore further to understand fully.

Our previous work has shown that those in groups at higher than average risk of an asthma attack are highly digitally literate[10], indicating that technology has the potential to be a key tool in preventing asthma attacks, and the positive results of this survey demonstrate that people with asthma want this technology to play a fundamental role in their healthcare. However, we're still in the preliminary stages. Our annual survey found that over half of people with asthma are already using some form of technology in their healthcare but very few had used an asthma specific app (8.3%) – demonstrating that there is still a huge unmet need for health technology in asthma monitoring and care[3].

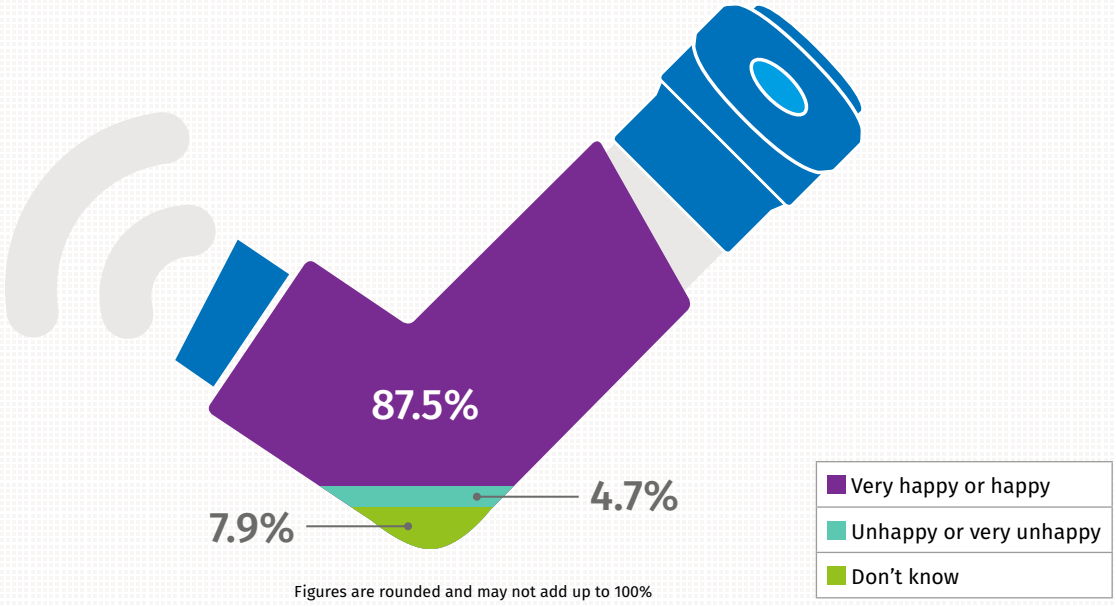
Respondents were also very positive about sharing data from new technologies with researchers (89.6%) if it helped drive improvements to asthma treatments and care.

Opinions on smart inhalers

"I always forget to take my medication even when I'm sick... [data would give me] help in the right direction"

Person with asthma

Figure 6: If smart inhalers were available on the NHS, how would you feel about using one?



87.5% of respondents (2672 of 3054) stated that they would be either 'very happy' or 'happy' to use a smart inhaler in their asthma management. Only a small proportion (4.7%, 142 of 3054) stated they would be unhappy to use such a device, indicating support from people with asthma for the adoption of smart inhalers if they are available through the NHS.

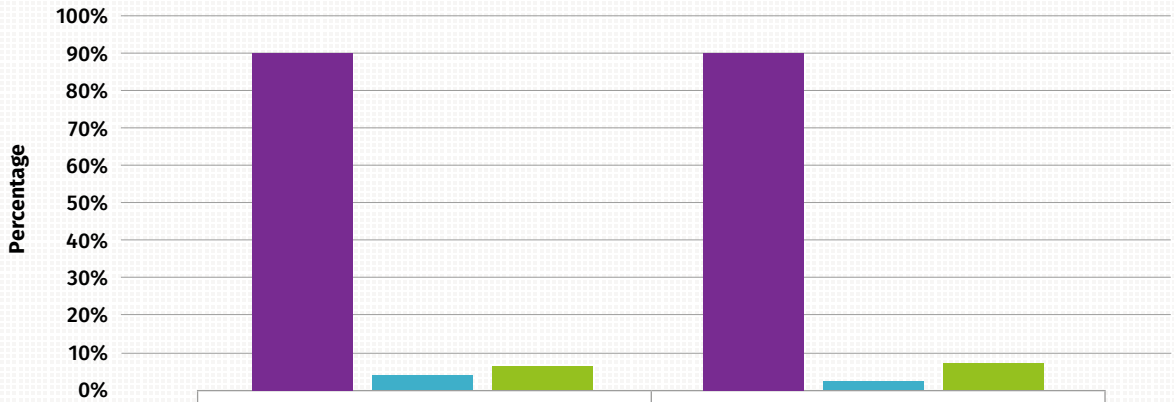
Smart inhalers can objectively track, monitor and prompt medication use via sensors that transmit adherence data to an accompanying mobile app[12]. The use of this precision data could help to identify those at risk, target highly personalised asthma guidance and enable appropriate interventions, but only if the data can be shared with their NHS health professional (e.g. their GP) through their electronic health record – which 90.0% of people with asthma would be happy to do.

Data sharing via smart inhalers

Respondents were similarly positive with data sharing via smart inhalers with healthcare professionals to inform care, and with researchers to help develop new treatments. 90.0% (2749 of 3054) would share their smart inhaler data with their healthcare professional, and 89.8% (2742 of 3054) would share smart inhaler data with researchers.

When the survey results were broken down by age, there were no significant differences in responses in either of the smart inhaler data sharing questions.

Figure 7: Data sharing via smart inhalers - *Would you be prepared for your health data to be shared in this way?*



	Data sharing from smart inhalers with your healthcare professional	Data sharing from smart inhalers for research
Yes	90.0%	89.8%
No	4.1%	3.2%
I don't know	5.9%	7.0%

Conclusions

THE FUTURE OF ASTHMA CARE AND RESEARCH

This report adds to the growing general body of literature on public attitudes on data sharing and reflects the increasing confidence that patients have in their data being used to improve healthcare and advance medical research.

The better utilisation of data and incorporation of new technologies into people with asthma's care holds significant promise for the delivery of an improved approach to asthma management. Currently we have a reactive approach to asthma management, with many people with asthma only interacting with healthcare services and engaging with their asthma during and soon after an attack. This has the potential to move us to a proactive approach where patient data is used to monitor and predict when someone is at risk of an asthma attack and needs to visit a health professional or make changes to their asthma management. To make this a reality, improved data sharing between healthcare services and the incorporation of technologies into NHS pathways is vital.

People with asthma are willing for their data to be used for reasons beyond their direct care in scenarios where the benefit is clearly communicated. This demonstrates the need for an honest and in-depth public dialogue about data sharing for secondary uses. It is also vital that sufficient safeguards are in place to protect patient privacy and ensure trust and confidence in how data is handled and maintained. Without this the benefits of data sharing will not be realised.

The level of support demonstrated by this survey makes asthma an ideal testing ground for the trial of new models of care enabled by innovative technologies and new data flows. The breadth of the asthma population, strong case for self-management and variety of care settings mean that asthma should be considered by government, industry, policy makers and research funders as an exemplar disease area to invest in for health technology and data sharing initiatives.

Key recommendations based on the findings of this report:

The confidence to take forward ideas and initiatives utilising new data streams and technologies from NHS local and national leaders is needed. People with asthma (1 in 11 of the UK population) see the benefits of data sharing and are supportive of data sharing initiatives. Getting it right for this group could pave the way for other conditions.

Continued and informed dialogue about the benefits and risks of data sharing by government, public bodies, charities and industry is needed. This is vital to build trust and make data-driven advancements to asthma research and services a reality.

Public attitude research is needed to understand the value of data sharing in different scenarios including the balance between benefit and risk, to inform data sharing policy development.

People with asthma are supportive about the use of technology and data in their care. Asthma should be considered as an exemplar condition for testing new initiatives enabled by technology due to the large-scale, representative, highly digitally literate and engaged population.

Appendix A – Results tables

Survey respondents

Table 1: Survey respondents by age and gender

Age	17 or under	18-29	30-39	40-49	50-59	60-69	70-79	80+	Total
Number of respondents	100	298	614	695	645	508	180	14	**3054**
% of total	**3.3%**	**9.8%**	**20.1%**	**22.8%**	**21.1%**	**16.6%**	**5.9%**	**0.5%**	**100.0%**
Women	45	256	561	599	562	417	136	8	**2584**
Men	55	38	52	94	83	91	44	6	**463**
Other	0	4	1	2	0	0	0	0	**7**

Table 2: Survey respondents by nation

Nation	Number	% of total
England	2356	**77.1%**
Northern Ireland	134	**4.4%**
Scotland	381	**12.5%**
Wales	183	**6.0%**
Total	3054	**100.0%**

Health data sharing scenarios

Table 3: Data sharing for research to develop new asthma treatments answers

	17 or under	18-29	30-39	40-49	50-59	60-69	70-79	80+	All ages
Very comfortable	30	95	181	188	189	131	46	6	**866**
Comfortable	32	99	204	262	204	210	68	3	**1082**
Uncomfortable	10	18	55	64	72	57	27	1	**304**
Very uncomfortable	0	7	11	94	83	91	44	6	**463**
I do not understand the question	2	3	3	3	4	1	1	0	**17**
Overall	**74**	**222**	**454**	**533**	**493**	**421**	**149**	**10**	2356
Very comfortable	40.5%	42.8%	39.9%	35.3%	38.3%	31.1%	30.9%	60.0%	**36.8%**
Comfortable	43.2%	44.6%	44.9%	49.2%	41.4%	49.9%	45.6%	30.0%	**45.9%**
Uncomfortable	13.5%	8.1%	12.1%	12.0%	14.6%	13.5%	18.1%	10.0%	**12.9%**
Very uncomfortable	0.0%	3.2%	2.4%	3.0%	4.9%	5.2%	4.7%	0.0%	**3.7%**
I do not understand the question	2.7%	1.4%	0.7%	0.6%	0.8%	0.2%	0.7%	0.0%	**0.7%**

Table 4: Data sharing to improve asthma services answers

	17 or under	18-29	30-39	40-49	50-59	60-69	70-79	80+	All ages
Very comfortable	30	99	183	205	185	143	43	5	**893**
Comfortable	37	108	234	269	232	212	83	4	**1179**
Uncomfortable	7	11	28	43	58	46	18	1	**212**
Very uncomfortable	0	3	8	11	17	20	5	0	**64**
I do not understand the question	0	1	1	5	1	0	0	0	**8**
Overall	**74**	**222**	**454**	**533**	**493**	**421**	**149**	**10**	**2356**
Very comfortable	40.5%	44.6%	40.3%	38.5%	37.5%	34.0%	28.9%	50.0%	**37.9%**
Comfortable	50.0%	48.6%	51.5%	50.5%	47.1%	50.4%	55.7%	40.0%	**50.0%**
Uncomfortable	9.5%	5.0%	6.2%	8.1%	11.8%	10.9%	12.1%	10.0%	**9.0%**
Very uncomfortable	0.0%	1.4%	1.8%	2.1%	3.4%	4.8%	3.4%	0.0%	**2.7%**
I do not understand the question	0.0%	0.5%	0.2%	0.9%	0.2%	0.0%	0.0%	0.0%	**0.3%**

Table 5: Data sharing for research to develop a tool to target people at risk of an asthma attack answers

	17 or under	18-29	30-39	40-49	50-59	60-69	70-79	80+	All ages
Very comfortable	37	122	247	257	230	188	57	5	**1143**
Comfortable	34	90	180	241	220	216	79	4	**1064**
Uncomfortable	**2**	8	20	25	33	15	12	1	**116**
Very uncomfortable	**0**	1	7	8	10	2	1	0	**29**
I do not understand the question	**1**	1	0	2	0	0	0	0	**4**
Overall	**74**	**222**	**454**	**533**	**493**	**421**	**149**	**10**	**2356**
Very comfortable	**50.0%**	55.0%	54.4%	48.2%	46.7%	44.7%	38.3%	50.0%	**48.5%**
Comfortable	**45.9%**	40.5%	39.6%	45.2%	44.6%	51.3%	53.0%	40.0%	**45.2%**
Uncomfortable	**2.7%**	3.6%	4.4%	4.7%	6.7%	3.6%	8.1%	10.0%	**4.9%**
Very uncomfortable	**0.0%**	0.5%	1.5%	1.5%	2.0%	0.5%	0.7%	0.0%	**1.2%**
I do not understand the question	**1.4%**	0.5%	0.0%	0.4%	0.0%	0.0%	0.0%	0.0%	**0.2%**

Data from new technology to improve asthma care

Table 6: Data sharing from apps and devices with your healthcare professional

	17 or under	18-29	30-39	40-49	50-59	60-69	70-79	80+	All ages
Yes	85	266	540	597	545	427	139	9	**2608**
No	6	12	23	35	29	15	13	2	**135**
I don't know	9	20	51	63	71	66	28	3	**311**
Total	**100**	**298**	**614**	**695**	**645**	**508**	**180**	**14**	**3054**
Yes	85.0%	89.3%	87.9%	85.9%	84.5%	84.1%	77.2%	64.3%	**85.4%**
No	6.0%	4.0%	3.7%	5.0%	4.5%	3.0%	7.2%	14.3%	**4.4%**
I don't know	9.0%	6.7%	8.3%	9.1%	11.0%	13.0%	15.6%	21.4%	**10.2%**

Table 7: Health data collected through apps and devices being combined with your medical records

	17 or under	18-29	30-39	40-49	50-59	60-69	70-79	80+	All ages
Yes	73	202	428	478	469	380	128	10	**2168**
No	2	34	66	63	40	30	10	0	**245**
I don't know	19	50	97	119	107	83	29	2	**506**
Total	**94**	**286**	**591**	**660**	**616**	**493**	**167**	**12**	**2919**
Yes	77.7%	70.6%	72.4%	72.4%	76.1%	77.1%	76.6%	83.3%	**74.3%**
No	2.1%	11.9%	11.2%	9.5%	6.5%	6.1%	6.0%	0.0%	**8.4%**
I don't know	20.2%	17.5%	16.4%	18.0%	17.4%	16.8%	17.4%	16.7%	**17.3%**

Table 8: Health data from apps and devices being used for healthcare decisions

	17 or under	18-29	30-39	40-49	50-59	60-69	70-79	80+	All ages
Yes	85	230	472	539	516	406	137	9	**2394**
No	0	5	3	8	4	2	3	0	**25**
I don't know	7	17	50	50	56	55	17	3	**255**
Total	**92**	**252**	**525**	**597**	**576**	**463**	**157**	**12**	**2674**
Yes	92.4%	91.3%	89.9%	90.3%	89.6%	87.7%	87.3%	75.0%	**89.5%**
No	0.0%	2.0%	0.6%	1.3%	0.7%	0.4%	1.9%	0.0%	**0.9%**
I don't know	7.6%	6.7%	9.5%	8.4%	9.7%	11.9%	10.8%	25.0%	**9.5%**

Table 9: Health data from apps and devices being used to determine when asthma needs to be reviewed

	17 or under	18-29	30-39	40-49	50-59	60-69	70-79	80+	All ages
Yes	84	234	478	558	533	427	140	10	**2464**
No	3	1	11	9	2	4	2	0	**32**
I don't know	5	12	33	22	37	30	12	2	**153**
Total	**92**	**247**	**522**	**589**	**572**	**461**	**154**	**12**	**2649**
Yes	91.3%	94.7%	91.6%	94.7%	93.2%	92.6%	90.9%	83.3%	**93.0%**
No	3.3%	0.4%	2.1%	1.5%	0.3%	0.9%	1.3%	0.0%	**1.2%**
I don't know	5.4%	4.9%	6.3%	3.7%	6.5%	6.5%	7.8%	16.7%	**5.8%**

Table 10: Health data from apps and devices being shared with researchers

	17 or under	18-29	30-39	40-49	50-59	60-69	70-79	80+	All ages
Yes	85	275	555	620	581	449	159	13	**2737**
No	4	8	18	15	20	15	3	0	**83**
I don't know	11	15	41	60	44	44	18	1	**234**
Total	**100**	**298**	**614**	**695**	**645**	**508**	**180**	**14**	**3054**
Yes	85.0%	92.3%	90.4%	89.2%	90.1%	88.4%	88.3%	92.9%	**89.6%**
No	4.0%	2.7%	2.9%	2.2%	3.1%	3.0%	1.7%	0.0%	**2.7%**
I don't know	11.0%	5.0%	6.7%	8.6%	6.8%	8.7%	10.0%	7.1%	**7.7%**

Opinions on smart inhalers

Table 11: Smart inhalers available on the NHS answers

	17 or under	18-29	30-39	40-49	50-59	60-69	70-79	80+	All ages
Very happy	56	172	332	372	342	248	80	7	**1609**
Happy	33	105	205	231	224	186	74	5	**1063**
Unhappy	2	7	22	20	22	19	5	0	**97**
Very unhappy	1	3	14	10	8	5	4	0	**45**
I don't know	8	11	41	62	49	50	17	2	**240**
Total	**100**	**298**	**614**	**695**	**645**	**508**	**180**	**14**	**3054**
Very happy	56.0%	57.7%	54.1%	53.5%	53.0%	48.8%	44.4%	50.0%	**52.7%**
Happy	33.0%	35.2%	33.4%	33.2%	34.7%	36.6%	41.1%	35.7%	**34.8%**
Unhappy	2.0%	2.3%	3.6%	2.9%	3.4%	3.7%	2.8%	0.0%	**3.2%**
Very unhappy	1.0%	1.0%	2.3%	1.4%	1.2%	1.0%	2.2%	0.0%	**1.5%**
I don't know	8.0%	3.7%	6.7%	8.9%	7.6%	9.8%	9.4%	14.3%	**7.9%**

Data sharing via smart inhalers

Table 12: Data sharing from smart inhalers with your healthcare professional

	17 or under	18-29	30-39	40-49	50-59	60-69	70-79	80+	All ages
Yes	95	273	548	621	584	455	160	13	**2749**
No	4	10	31	30	23	20	8	0	**126**
I don't know	1	15	35	44	38	33	12	1	**179**
Total	**100**	**298**	**614**	**695**	**645**	**508**	**180**	**14**	**3054**
Yes	95.0%	91.6%	89.3%	89.4%	90.5%	89.6%	88.9%	92.9%	**90.0%**
No	4.0%	3.4%	5.0%	4.3%	3.6%	3.9%	4.4%	0.0%	**4.1%**
I don't know	1.0%	5.0%	5.7%	6.3%	5.9%	6.5%	6.7%	7.1%	**5.9%**

Table 13: Data sharing from smart inhalers for research

	17 or under	18-29	30-39	40-49	50-59	60-69	70-79	80+	All ages
Yes	93	274	556	622	584	444	157	12	**2742**
No	4	7	25	19	15	21	8	0	**99**
I don't know	3	17	33	54	46	43	15	2	**213**
Total	**100**	**298**	**614**	**695**	**645**	**508**	**180**	**14**	**3054**
Yes	93.0%	91.9%	90.6%	89.5%	90.5%	87.4%	87.2%	85.7%	**89.8%**
No	4.0%	2.3%	4.1%	2.7%	2.3%	4.1%	4.4%	0.0%	**3.2%**
I don't know	3.0%	5.7%	5.4%	7.8%	7.1%	8.5%	8.3%	14.3%	**7.0%**

Appendix B – Survey questions

Questions about survey respondents

1. Are you:
a. 17 or under
b. 18-29
c. 30-39
d. 40-49
e. 50-59
f. 60-69
g. 70-79
h. 80+

2. What is your gender?
a. Male
b. Female
c. Other

3. Where do you live?
a. England
b. Northern Ireland
c. Scotland
d. Wales

4. Which region do you live in?
[If answer England]
a. East Midlands
b. East of England
c. London
d. North East
e. North West
f. South East
g. South West
h. West Midlands
i. Yorkshire and the Humber

[If answer Northern Ireland]
a. Belfast
b. Northern
c. South Eastern
d. Southern
e. Western

[If answer Scotland]
a. Ayrshire and Arran
b. Borders
c. Dumfries and Galloway
d. Fife
e. Forth Valley
f. Grampian
g. Greater Glasgow and Clyde
h. Highlands and Western Isles
i. Lanarkshire
j. Lothian
k. Orkney and Shetland
l. Tayside

[If answer Wales]
a. Abertawe Bro Morgannwg
b. Aneurin Bevan
c. Betsi Cadwaladr
d. Cardiff and Vale
e. Cwm Taf
f. Hywel Dda
g. Powys

Questions about health data sharing scenarios

We're going to ask you about ways information from your healthcare record can be used and what you think about it.

Some of the following questions ask your opinion on the use of your **"confidential patient information"**.

This is any information that identifies you personally and could include information about your physical or mental health, for example, diagnosis of your condition or treatment.

Another term that will be used is **"anonymised patient information"**. You can't be identified through this or through the combination of this information with other information.

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5. Severe asthma affects between 200,000-250,000 people in the UK and includes types of asthma that do not respond to current treatments. Research is needed into severe asthma so that new treatments can be developed.

So - a group of scientists at a university need access to confidential patient information from a large group of people with severe asthma. They plan to use this person-level information to identify trends to understand more about severe asthma and help develop new treatments.

In an example such as this, how comfortable would you be with your data being used in this way?

a. Very comfortable
b. Comfortable
c. Uncomfortable
d. Very uncomfortable
e. I do not understand the question

6. Your local NHS services wish to access relevant parts of your confidential patient information to better understand use of healthcare services by people with asthma. For example, this could look at who receives follow-up GP appointments after attending A&E for an asthma attack.

Analysing this data will help your local NHS better understand if and when people with asthma receive follow-up care and their experience of healthcare.

In an example such as this, how comfortable would you be with your data being used in this way?

a. Very comfortable
b. Comfortable
c. Uncomfortable
d. Very uncomfortable
e. I do not understand the question

7. A local hospital is working in partnership with an analytics company to develop a new tool that will help identify the people with asthma at risk of having an asthma attack. The hospital will use anonymised patient information of all adults with asthma in the area. By looking at the anonymised records, the analytics company hopes to develop a tool to help the hospital understand who is most at risk and so help prevent asthma attacks.

In an example such as this, how comfortable would be with your data being used in this way?

a. Very comfortable
b. Comfortable
c. Uncomfortable
d. Very uncomfortable
e. I do not understand the question

Questions about using data from new technology to improve asthma care

Next we're going to ask you about your thoughts on information collected from new technology.

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8. Information about your asthma can be collected through new technologies. Examples include mobile apps (e.g. symptom tracking apps, lifestyle and fitness apps) and wearable devices (e.g. a fitness tracker, such as an Apple watch or Fitbit). In the future, these technologies could be useful to help you manage your asthma and to tell healthcare professionals how your asthma has been over time.

Would you be prepared, with your consent, for information relevant to your asthma that has been collected by these types of technology to be shared with your asthma healthcare professional?

a. Yes
b. No
c. I don't know

9. [If answered 'No'] If you wish, please tell us why.
a. [Free text]

10. Would you want relevant information collected by health apps and devices about your asthma to be included in your medical record?
a. Yes
b. No
c. I don't know

11. [If answered 'No'] If you wish, please tell us why.
a. [Free text]

12. Would you welcome the use of this information (collected by apps or devices) being used by healthcare professionals to help inform their decisions made about your asthma care?
a. Yes
b. No
c. I don't know

13. [If answered 'No'] If you wish, please tell us why.
a. [Free text]

14. If data collected by apps or devices was shared with your healthcare professional, would you be prepared for this information to be used to tell you when your asthma needs to be reviewed by a healthcare professional?
a. Yes
b. No
c. I don't know

15. [If answered 'No'] If you wish, please tell us why.
a. [Free text]

16. Would you be willing to share information from a new technology in an anonymised format with researchers to help drive improvements to asthma treatments and care?
a. Yes
b. No
c. I don't know

17. [If answered 'No'] If you wish, please tell us why.
a. [Free text]

Questions about opinions on smart inhalers

Smart inhalers detect inhaler use and transmit that data. They contain a sensor that records when your medication is taken. This can be used to monitor your inhaler use and send you reminders to use your asthma inhaler. The data from a smart inhaler could be shared with your GP, asthma nurse or hospital team to help tailor care to your needs.

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18. If smart inhalers were available via the NHS, how would you feel about using one?
a. Very happy
b. Happy
c. Unhappy
d. Very unhappy
e. I don't know

Questions about data sharing via smart inhalers

19. Would you be prepared to share information collected from your smart inhaler with your GP, asthma nurse and/or hospital team to inform the care that you receive?
a. Yes
b. No
c. I don't know

20. Would you be prepared to share the information collected from a smart inhaler with asthma researchers to help them learn more about asthma and the development of new treatments?
a. Yes
b. No
c. I don't know

Please note: We asked further questions about artificial intelligence in the survey. We will publish the results of these questions in a subsequent briefing.

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All hyperlinks in the references above, and elsewhere in the report as a whole, are accessible as of May 2018.

Every ten seconds someone in the UK has a potentially life-threatening asthma attack and three people die every day. Tragically two thirds of these deaths could be prevented, whilst others still suffer with asthma so severe current treatments don't work.

This has to change. That's why Asthma UK exists. We work to stop asthma attacks and, ultimately, cure asthma by funding world leading research and scientists, campaigning for change and supporting people with asthma to reduce their risk of a potentially life-threatening asthma attack.

We fight asthma in three ways:

- We fund world class asthma research.
- We campaign to improve the quality of care received by people with asthma.
- We help hundreds of thousands of people a year with our expert advice and support.

To find out more about Asthma UK's work:

Asthma UK Helpline:
0300 222 5800

Email us:
info@asthma.org.uk

Visit our website:
www.asthma.org.uk

Find us on facebook:
www.facebook.com/asthmauk

Follow us:
@asthmauk
@AUKResearch