

# Next Generation Asthma Care

## Position Paper

## Introduction

As Scotland's national innovation centre for digital health, DHI works collaboratively with partners across the UK to support transformational innovation in digital health and care, engaging industry, academia, citizens and third sector to co-design digital solutions to some of Scotland's biggest health and care challenges.

This paper introduces Next Generation Asthma Care (NGAC), a collaborative research project led by the Digital Health and Care Institute (DHI) with input from Asthma UK. Asthma UK is the UK's only dedicated asthma charity and works 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.

It is acknowledged that a significant proportion of the morbidity and mortality around asthma is preventable, for example; two thirds of asthma deaths are preventable through better basic care. (Royal College of Physicians, Why Asthma Still Kills, 2014)<sup>1</sup>. Similarly, asthma co-management has the potential to be significantly improved through the utilisation of technology and service redesign to create a data rich environment. This project aims to explore the potential of citizen-generated data being used to drive improved, meaningful and sustainable co-management models of care. Key to this is an understanding of the barriers and enablers for adoption of such models at scale and a better understanding of trust in a digital context.

This work draws upon a strong academic and industry research base and is closely aligned with Asthma UK's published policy reports on digital health: Connected Asthma (2016)<sup>2</sup>; Smart Asthma (2017)<sup>3</sup>; and Data sharing and technology: Exploring the attitudes of people with asthma (2018)<sup>4</sup>. Responding to the key findings emerging, NGAC will address challenges around the design, usability and integration of new user-centred technologies; interoperability across health, care and consumer systems; and supporting technology-enabled self-management. This project will engage people living with asthma and health professionals delivering asthma care to co-design new approaches, interventions and ideas that explore how asthma care might be delivered in the future.

From a policy perspective, this work is also aligned to UK and Scottish Government policies, for example the UK government's industrial strategy through exploring opportunities for next generation networking as detailed in the strategy document Next Generation Mobile Technologies (UK Government 2018)<sup>5</sup>; health and social care integration through the promotion of citizen-centred data sharing; and the strategies of realistic medicine which aim to put the people rather than services at the centre of health and care transformation

## The Problem

Asthma is now one of the most common long-term conditions in the UK (Mukherjee et al., 2014)<sup>6</sup> and within Scotland, prevalence amongst the highest in the world, representing over 368,000 people (Scottish Government, Scottish Health Survey 2003)<sup>7</sup>. A significant public health challenge, asthma is recognised as the second most common chronic illness presenting in primary care (Weatherburn et al., 2017)<sup>8</sup> and Scotland is acknowledged as having some of the poorest health outcomes for asthma (Soyiri et al., 2018)<sup>9</sup>. The daily impact of asthma can be considerable and the extent and duration of asthma as a disability is acknowledged (Global asthma report, 2014)<sup>10</sup>. Furthermore, the physical, social and emotional impact of asthma reflects the multiplicity of the condition and highlights the contribution of everyday interactions to managing the episodic, and chronic manifestations of asthma (Nunes, 2017)<sup>11</sup>.

Self-management is recognised as an established and effective approach to controlling asthma however the uptake of such practices is low and poor control of asthma is understood to be a significant factor in over 50% of cases (Miles et al., 2017)<sup>12</sup>. While the use of technology as a driver for encouraging better self-management is recognised (Miles et al., 2017)<sup>12</sup>, adoption may be limited by the digital-skills capacity of the individuals involved and significant challenges around privacy, trust, data collection and ownership and the associated system architecture (Bélanger & Crossler, 2011)<sup>13</sup>; (Martin & Murphy, 2017)<sup>14</sup>; (Fox & Connolly, 2017)<sup>15</sup>.

New models of care are required, taking account of the individual, environmental and social factors that play a role in the management of the condition. Models of self-management are becoming increasingly important for the provision of care for long-term conditions, shifting the focus from primary and secondary care providers towards a collaboratively-managed context and have been recognised as preferable (Pinnock et al., 2015)<sup>16</sup>. This project aims to address these key challenges, building upon the body of evidence to explore future models of care for asthma in Scotland.

## Opportunities for Digital Asthma Care

Despite growth of new technological approaches to health, digital innovation across asthma care is recognised as fragmented. Investment in user-centred design, innovation validation, industrial scaling and establishing the health economics of new models of care are understood to be drivers for future growth (Asthma UK, 2016)<sup>2</sup>. The deployment of existing and new technology, as well as the integration and interoperability of data between citizens and health and care providers is critical for tech-enabled asthma management.

In comparison to other similar conditions, asthma can be considered 'data poor'. The existing focus of data collection is face-to-face interaction during annual review however new technological approaches could offer more opportunities for real-time data capture and curation (Asthma UK, 2016)<sup>2</sup>. One such example is smart inhalers; an established technology already being used in the US and in clinical trials in the UK. Passive data collection (e.g. data collected by a device without the individual having to enter information) is recognised as key for asthma technology to be widely adopted and smart inhalers have been heralded as a particularly promising technology to drive technology enabled transformation asthma management. Smart inhalers 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 (i.e. people not adhering to prevention medication or experiencing symptoms that need review).

Beyond smart inhalers, other technological approaches also offer promising data insights towards helping people to better manage their own asthma, for example wearables; mobile applications; other self-monitoring connected devices. When combined with other data sources, such technology has the potential to predict the likelihood of asthma attacks; aid clinical decision making; and drive better targeting of healthcare resources. However, further validation is required to explore these further.

There is also a shift in the amount of people willing to make use of their data for the common good. A recent survey of asthma patients in the UK found that 94% of those surveyed would be willing for their anonymised health data to be used by an analytics company, in partnership with the NHS, to better identify people at risk of an asthma attack. It was recently found that 83% of people with asthma are comfortable with their confidential health data being shared for research to develop new asthma treatments (Asthma UK, 2018)<sup>4</sup>. Therefore, through this culture shift, combined with contextual data and service redesign, asthma has the potential to become a data rich and co-managed condition.

## Work Package Summary

DHI will combine co-design research activity with digital infrastructure exploration to explore the transformative potential of citizen-generated data towards improved, meaningful and sustainable co-management models of care. This will support a better understanding of how predictive, co-managed and scalable digital asthma technologies could be designed and implemented.

The insights gathered during this work package will ensure that emerging service models, technology proposals and use of data is acceptable and meaningful to users, families and health care providers as well as ensuring that the technical specification is relevant and sustainable. This will also include engaging with other centres to ensure clinical effectiveness and involving industry to test market readiness and scalability.

The second work package is technology focused and is framed around the premise that in order to fully maximise the value of citizen generated data for preventative care at scale, we must understand how to combine the 'Internet of Things' with emerging networking and trust architecture capabilities to collect the data in a manner that is low effort, reliable, cheap and that meets the user's control and privacy expectations. This will be explored through explorations of trust: trust in technology; trust in data sharing; and trust between citizens and care providers. Using the DHI's simulation environment, co-designed service model can be combined with potential future architecture to demonstrate solutions for a data rich co-managed environment for asthma. This will then be available to others to undertake further research and development, with key development opportunities emerging identified throughout.

## Existing Research and Development Activity

This project is aligned to a significant body of existing and ongoing research and development activity within this constantly changing landscape. In the UK, there are streams of work that are exploring concepts of trust within data sharing in the health and care domain as well as other projects that are looking specifically at new models of digital asthma care.

Organisation	Project Activity
Health data Research UK	Received £37.5m investment from the industrial strategy fund to faster develop treatments for health conditions including asthma by connecting regional health and care data with biomedical data in secure environments: <a href="http://www.hdrk.ac.uk/news/37-5m-investment-in-digital-innovation-hubs">www.hdrk.ac.uk/news/37-5m-investment-in-digital-innovation-hubs</a>
The Wellcome Trust	Involved in the exploration of data sharing methodologies and the underlying trust that needs to be in place to make data sharing more dependable. The Wellcome Trust commissioned Ipsos Mori to conduct social research to assess the public's perception of commercial access to health data. In addition to leading the public attitudes to commercial access work, they've supported a number of other public attitudes studies and developed a lot of useful resources including the Understanding Patient Data portal: <a href="http://www.understandingpatientdata.org.uk">www.understandingpatientdata.org.uk</a>
Sensor City	Liverpool-based technical innovation centre and University Enterprise Zone. The Innovation centre has been awarded £3.5m grant funding from the UK government to investigate the opportunities of next generation community wi-fi in health and social care contexts: <a href="http://www.sensorcity.co.uk">www.sensorcity.co.uk</a>
Northwest London health board	Dedicated resources to whole systems integrated care to create an ecosystem of care whereby staff and citizens have access to the right information and data in an integrated system which in turn encourages people to better manage their own health and well-being. They have also developed an asthma specific dashboard, used as a case study on pg. 5 of Asthma UK's report: <a href="http://www.asthma.org.uk/globalassets/get-involved/external-affairs-campaigns/publications/data-report/data-sharing-and-technology---exploring-the-attitudes-of-people-with-asthma.pdf">www.asthma.org.uk/globalassets/get-involved/external-affairs-campaigns/publications/data-report/data-sharing-and-technology---exploring-the-attitudes-of-people-with-asthma.pdf</a>
Chatham House	Exploring principles for sharing health data and in particular the principle of trust that is required for public health surveillance. <a href="http://www.chathamhouse.org">www.chathamhouse.org</a>
The Open Data Institute	Carried out a survey carried out with the UK public in conjunction with YouGov to better understand the British Public's attitudes to sharing of personal data. <a href="http://www.theodi.org">www.theodi.org</a>

Organisation	Project Activity
National Institute for Health and Care Excellence	Briefing reporting on randomised controlled trials with people with asthma who used smart inhalers in a community setting suggests that while smart inhalers were effective in improving adherence to asthma medication, further studies and health economic analysis of smart-enabled care pathway is required. <a href="http://www.nice.org.uk/advice/mib90">www.nice.org.uk/advice/mib90</a>
The National Data Guardian for Health and Care	Reviewed data security, consent and opt-outs, considering trust in data sharing: <a href="http://www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/668729/NDG_Progress_Report_FINAL_v1.1.pdf">www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/668729/NDG_Progress_Report_FINAL_v1.1.pdf</a>
NHS UK Government Scottish Government	From a policy perspective, the Scottish Digital Health and Care Strategy; TEC Delivery Plan; Life Science strategy for Scotland: 2025 vision; Realistic Medicine; NHSE Five year forward view; and the UK Life Science Industrial strategy highlight a commitment to exploration of future models of care, with an emphasis on the potential of digital to enable and equip towards sustainable health and care delivery: <a href="http://www.gov.scot/Resource/0053/00534657.pdf">www.gov.scot/Resource/0053/00534657.pdf</a> <a href="http://www.gov.scot/Resource/0051/00515583.pdf">www.gov.scot/Resource/0051/00515583.pdf</a> <a href="http://www.lifesciencesscotland.com/wp-content/uploads/2017/08/Life-Sciences-Strategy-for-Scotland-2025-VisionFINALlow-res.pdf">www.lifesciencesscotland.com/wp-content/uploads/2017/08/Life-Sciences-Strategy-for-Scotland-2025-VisionFINALlow-res.pdf</a> <a href="http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf">www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf</a> <a href="http://www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/666359/171206_Industrial_Strategy_Life_Sciences_SD_Accessible_PDF_DPS.pdf">www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/666359/171206_Industrial_Strategy_Life_Sciences_SD_Accessible_PDF_DPS.pdf</a>

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