

Developing a shared definition of self-driven healthcare to enhance the current healthcare delivery paradigm

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The world's ageing population is experiencing a growing epidemic of multimorbidity and non-communicable diseases, including cancer, obesity, type II diabetes and cardiovascular disease. At the same time, the underuse of evidence based self-care interventions and the ineffective application of scarce resources is widening the gap between supply and demand against a backdrop of stark inequalities exacerbated since the advent of the COVID-19 pandemic. Unless these challenges are addressed, future generations may live with diminished access to healthcare at increased costs. Innovation can play a significant role in addressing these challenges, and in particular those innovations that deliver 'self-driven' healthcare (SDH) solutions to promote citizen engagement and streamline access to evidence-based self-care interventions in the community setting.

The quantified self and the emergence of Society 5.0

In the UK and most high-income settings, the patient role is rapidly shifting away from being a passive actor and information receiver to becoming an empowered self-carer with the ability to share self-generated data and participate in decision-making to inform their health and wellbeing journey.¹ The healthcare industry is responding by digitising its service provision to provide personalised healthcare and more effective care models.² The pervasive use of technology, smartphone apps and remote monitoring devices has also led to a growing phenomenon of self-measurement exemplified by individuals who observe and monitor their own health.³ This movement of 'self-quantification' is supported by an ever-increasing array of in vitro diagnostic and point-of-care tests, consumer-based smart wearables and digital therapeutics. Key literature and technology market indicators predict that self-tracking and

mastering self-care will be an increasingly growing trend that will positively impact how healthcare is delivered, while informing the development of new person-driven healthcare models. At the same time, healthcare professionals (HCPs) are upskilling and quickly realigning to integrate this trend in the design and delivery of new services in healthcare organisations.⁴ This shift is rapidly disrupting the prevailing paternalistic healthcare model, especially following the advent of COVID-19 and the emergence of Society 5.0, which will be defined by the pervasive use of technologies such as artificial intelligence (AI), big data, the internet of things, drones, blockchain and 3D printing.^{5,6}

By promoting choice, empowerment and enhancing individual self-care capability, national institutions can help maximise the efficient use of domestic resources for health, and nurture innovation in the health sector, including the development of digital therapeutics while improving access to medicines and interventions for patients and public alike.^{7,8} All of this is creating a new opportunity for value co-creation in healthcare using an SDH approach.

Self-driven healthcare

Self-driven healthcare is an umbrella term introduced by Innovate UK to conceptualise aspects of healthcare delivery that can support people in becoming more engaged in their own health and wellbeing management rather than being passive receivers of healthcare. The defining characteristics of SDH include activities that empower people to play a more effective role in maintaining their own health and wellbeing, including those activities concerned with primary prevention and health promotion (e.g. detecting diseases earlier and proactively

collaborating with a growing range of HCPs to manage their illnesses).

The SDH approach is facilitated by building a more personal and private healthcare infrastructure around people using consumer-focused monitoring and diagnostic tools connected to accessible online portals. The vision for SDH is that these personal healthcare management systems are integrated with the wider healthcare system, including the National Health Service (NHS). SDH would support better online interaction with HCPs and improve the exchange of information, including shareable personal healthcare records and self-generated data. By building a personal healthcare infrastructure capability that connects people to the wider healthcare system, SDH also has the potential to integrate a wider range of activities, such as AI-guided clinical coaching, predictive, preventative, personalised, participatory medicine and home clinical trials (Figure 1).

When applied at scale, SDH ecosystems could help governments and health organisations, including the NHS, to achieve their ambition of improving health outcomes while controlling costs and addressing priority areas such as equality, diversity and inclusion (EDI), levelling up and Net-Zero. The development of SDH also presents an opportunity for the UK to build and grow companies in this area with a large international market. Innovate UK is committed to working with a wide range of stakeholders to develop a shared definition of SDH. Refining the vision for the SDH roadmap is

important to support healthcare delivery, as more people engage with self-quantification as we enter Society 5.0.

SDH scenario 2030

SDH can be used by healthy individuals, consumers of health technology products and patients across a variety of settings to promote personal empowerment and individual self-care capability (Figure 2). A desirable SDH ecosystem will support activated individuals in taking more ownership of their health and wellbeing journey and in recording their own data (e.g. weight, blood pressure, etc.) using a phone app, tablet, computer or Bluetooth device. They might upload these self-generated data onto a blockchain-secure online portal (or platform) that holds all their health records, including those generated in the wider healthcare system.

In this scenario, activated individuals would also enter other data, such as what medication they had taken that day, the food they had eaten or the exercise they had done. They may even have a range of other devices that automatically record and upload useful information, such as environmental data about local air quality that day. The SDH portal would offer a personalised dashboard that would automatically present the user with their ‘digital twin’. The SDH portal may also be enabled to routinely provide insights and actionable advice to the self-carer, including microlearning and behaviour change interventions and a holistic picture of the

Figure 1. Schema showing the ideal characteristics of an SDH portal. Self-generated data could be shared by the individual ‘self-carer’ (who could be a healthy person or a patient) to a secure SDH portal. The SDH portal will have added functionality and could provide personalised feedback and actionable insights to empower the self-carer and promote the adoption of health-seeking self-care behaviours.

POCT: point of care test; IVD: in vitro diagnostic; NHS: National Health Service; SDH: self-driven healthcare.

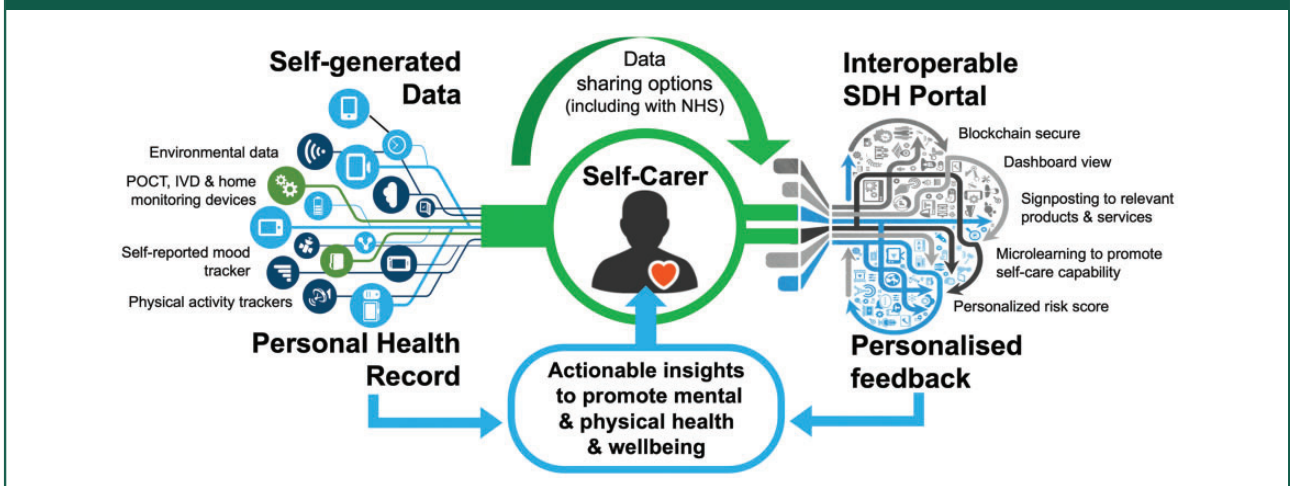
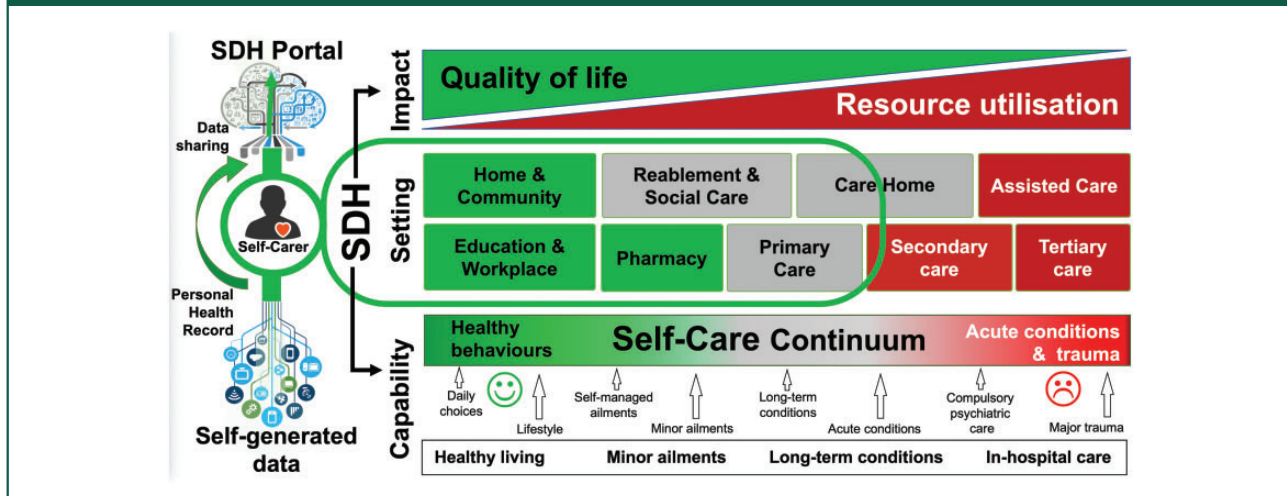


Figure 2. Schema illustrating the various settings where individuals and providers can apply the SDH approach to promote individual self-care capability. SDH: self-driven healthcare.



person's overall health and wellbeing status. A desirable SDH ecosystem would facilitate better self-care and management with an emphasis on maintaining health and not just treating illness.⁹ This approach would also improve early (pre-symptomatic) detection of disease by warning if a significant change in healthcare status was identified, perhaps using AI-powered online diagnostic tools.

As the portal is integrated with the wider public or national healthcare system, it can facilitate activities such as online consultations with HCPs, including a general practitioner (GP) or pharmacist, even allowing them access to self-generated health data records. If specialist treatment were needed, the initial consultation, monitoring and follow-up process could still be facilitated via the online portal to reduce trips to hospitals or clinics, for both acute and chronic conditions. In this way, the SDH solution may facilitate a wider range of other health and wellbeing activities, such as managing prescriptions, monitoring treatment plans, providing educational material, connecting with other people with similar conditions as part of a support group, or even providing online treatments such as cognitive behaviour therapy.

A desirable SDH approach could be encapsulated by someone having a range of these portals connected to their computer or as apps on their phone. In the long term, it is more likely that people would want a single main portal that is modular in nature and links to a range of providers and services, akin to a healthcare 'Facebook'. In the UK, the NHS might build such an environment by 2030, and this may be the future direction for the NHS App, as this already allows access to NHS data and allows people to

perform functions such as booking GP appointments and ordering prescriptions.

SDH business models

Many of the component parts of the SDH scenario described already exist and Innovate UK has already funded activity in this area, but often this did not result in the development of a sustainable SDH ecosystem. One of the reasons there has been limited success is related to issues with healthcare data access and security. Second, even successful innovations that tried to integrate the use of wearables or home diagnostic kits often resulted in the creation of fragmented 'digital silos' or a specific way for the user to access their personal health record (PHR) without integration with the wider data economy. These barriers are difficult for companies, integrated care systems or the NHS to tackle alone. Conversely, national funding agencies like Innovate UK could help address these barriers, such as for example by helping to build an enabling SDH infrastructure that spans across consumer, community, pharmacy and general practice (primary care).

More could also be done to streamline the integration of data with the wider health and social care system pending the consent of the end-user to relinquish some of their self-generated data to an SDH portal. A community-facing SDH portal could be secured using blockchain and will have added functionality such as providing the end user (the self-carer) with a dashboard, PHR, actionable insights and personalised risk scores, coaching and behaviour change interventions.

Introducing self-driven healthcare as an umbrella term could signal the development of cross-cutting healthcare innovations designed to operate at system level and therefore help address some of the barriers that hindered the success of earlier SDH attempts. When digital health companies are developing their online innovations, it is more efficient if they can use platforms and ‘off-the-shelf’ components that allow them to concentrate on their area of expertise and innovation, and not have to reinvent the wheel or build disconnected digital silos. This would be particularly important in areas concerned with accessing or storing health data securely, having integrated and interoperable systems, secure commercial environments or when integrating a more holistic approach to improving motivation.

SDH call to action

Health system sustainability is a construct of both economic and social sustainability, as both are needed for the system to guarantee accessible and adequate care for all citizens and satisfy their needs.¹⁰ An effective SDH approach could help governments and health organisations, such as the NHS, achieve their ambition to improve health outcomes, reduce costs and address priority areas including EDI, Net-Zero and Build Back Better. For areas such as EDI and levelling up, the SDH approach must create better access to all sections of the community rather than just wealthier and more technically literate individuals. As SDH is likely to be technology driven, it is also crucial to ensure the movement does not exacerbate inequalities due to the digital divide.¹¹

Self-driven healthcare is one area that may, in the future, benefit from investment to help promote the evolution of congruent SDH ecosystems, and to address other system gaps including the development of a universal SDH platform. This could be similar to the computer operating system analogy proposed in the 2030 scenario above and could be made available as a public good to drive up uptake of the technology, and foster opportunities for collaboration and innovation.

While SDH could be seen as an evolution rather than a revolution of current healthcare systems, how it is adopted in the future is very important, especially when it is applied to help enhance the non-NHS consumer health system by trying to link it effectively with state-funded NHS health and social care systems. Given that considerable activity is likely to be delivered via online ‘SDH portals’ it will be important to determine if these will be provided by the NHS, such as by expanding the NHS App for example, or if these online environments will be provided by commercial companies.

The UK is a significant exporter of a world-leading knowledge economy, and the development of SDH presents a key opportunity for the UK to build and grow companies with a large international market share. Innovate UK is looking to engage with a range of stakeholders to assess the opportunities and challenges of the SDH approach and determine if this is an area of healthcare it should support. As SDH is a new term, Innovate UK established the SDH Open Advisory Group and is looking for stakeholder feedback and engagement to help refine the roadmap for how this sector could be developed.¹²

Conclusion

The development and integration of person-centred SDH solutions will be key to drive up personal empowerment, quality of life and health and well-being outcomes, and deliver more sustainable health systems. Future deliberations will assess the opportunities and challenges of developing a sustainable SDH ecosystem in the UK and determine if this is an area of healthcare that Innovate UK should support and export internationally as a global good.

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References

1. Akenroye TO. Factors influencing innovation in healthcare: a conceptual synthesis. *Innovation J* 2012; 17: 1.
2. Caulfield B and Donnelly S. What is connected health and why will it change your practice? *QJM: Int J Med* 2013; 106: 703–707.
3. Almalki et al. Health Information Science and Systems 2015, 3(Suppl 1):S1 <http://www.hissjournal.com/content/3/S1/S1>

4. WHO. Transforming lifelong learning for health impact 2021. See www.who.int/about/who-academy (last checked 3 November 2022).
5. Deguchi A, Hirai C, Matsuoka H, Nakano T, Oshima K, Tai M, et al. What is Society 5.0? *Society 5.0: a people-centric super-smart society*. Singapore: Springer Singapore, 2020: 1–23.
6. El-Osta A, Qualter P and Goldman N. Loneliness & Society 5.0: a public lecture delivered on 12 May 2022 to celebrate Mental Health Awareness Week 2022. Mental Health Awareness Week. See <http://hdl.handle.net/10044/1/100039> (last checked 12 May 2022).
7. WHO. What do we mean by self-care? See www.who.int/news-room/feature-stories/detail/what-do-we-mean-by-self-care (last checked 3 November 2022).
8. WEF. Self-care can help to ease the strain on our health systems. Here's how. World Economic Forum. See www.weforum.org/agenda/2020/12/3-ways-self-care-can-help-us-to-rebuild-healthcare/ (last checked 3 December 2020).
9. El-Osta A, Webber D, Gnani S, Banarsee R, Mummery D, Majeed A, et al. The self-care matrix: a unifying framework for self-care. *Self-Care* 2019; 10: 38–56.
10. Russo G, Tartaglione AM and Cavacece Y. Empowering patients to co-create a sustainable health-care value. *Sustainability* 2019; 11: 1315.
11. Maile A EJ and Coronini-Cronberg S. Covid-19 is magnifying the digital divide. *BMJ Opin* 2020. <https://blogs.bmj.com/bmj/2020/09/01/covid-19-is-magnifying-the-digital-divide/>
12. El-Osta A. Characterising barriers & drivers for the sustainable adoption of self-driven healthcare (SDH). Imperial College London Qualtrics; participant information sheet. See https://imperial.eu.qualtrics.com/CP/File.php?F=F_42ggyGF3A6ZIW5g (last checked 3 November 2022).