

Care Alliance Ireland Submission

Updating the Digital Health and Social Care Strategic Framework for Ireland 2023-2030

May 2023

Introduction

Care Alliance Ireland are pleased to create this submission in response to our recent invitation by the Department of Health (DoH) and the Health Services Executive (HSE) to a consultation on the development of the updated Digital Health and Social Care Strategic Framework for Ireland 2023-2030.

In early 2023, we made a number of representations by email to key actors in the Department of Health and in the HSE enquiring as to the status of a commitment made to publishing a follow up to the 2013 eHealth Strategy.

On May 12th, 2023, we were invited to take part in a stakeholder meeting through the HSE National Patient Forum.

On May 16th, 2023, our CEO Mr. Liam O'Sullivan and our Senior Policy and Research Officer, Ms. Zoe Hughes, took part in this stakeholder meeting.

For comprehensiveness, we include below some of the points we made verbally at that meeting of May 16th, 2023, under the topic 'key issues'. We then make particular reference to our responses to the three questions posed by the DoH and HSE officials in advance of this meeting.

We look forward to ongoing discussions and collaboration with Department of Health officials, HSE officials, our colleagues in the not-for-profit sector and other relevant stakeholders.

Background: Care Alliance Ireland Experience in the Delivery of Online Health and Wellbeing Interventions

Care Alliance Ireland has significant experience within the field of online health and wellbeing interventions. Our current Strategic Plan (2019-2024) includes particular reference to developing innovative online interventions for family carers. Work on this topic began in Care Alliance in advance of 2019 with collaborative projects such as our Friendsourcing project (in collaboration with Indiana University and the Alzheimer Society of Ireland) and Towards Resilience in Family Caregiving for People with Dementia (EnCaRe) project in collaboration with University College Dublin.

Our Online Family Carer Support Project¹, set up in March 2020 as Covid-19 began, is now supporting in excess of 5,300 family carers. Over 80% of these family carers were not availing of face-to-face supports heretofore. This tells us that there exists a significant opportunity to reach and engage with large cohorts of our population, for whom access to these supports has been an issue to date. We have been in receipt of modest funding (€100,000) from the HSE for this project since 2021 under The Carers Guarantee/National Dementia Office.

As an organisation we have developed links with academics and practitioners across the world with an interest in the provision of online social care supports. Most recently, our CEO Liam O'Sullivan has co-authored the book *Social Work in an Online World: A Guide to Digital Practice* (April 2023)².

Key Issues

1) Wording choices and the impact on digital service delivery

We understand that the current significant issue in the realm of eHealth in Ireland is that of electronic health records (EHRs). The benefits that the provision of such records would provide for staff working within the health & social care system, patients, their family carers and the public in general is clear. We in Care Alliance strongly believe that the development of EHRs will provide potential for streamlined care and more appropriate healthcare across the country. It is also a right of patients to be able to access their own personal health records, and where appropriate the records of those they care for, in order to be empowered in their own healthcare.

However, eHealth encompasses more than just electronic medical health records, and we are firmly of the view that any future policy and practice needs to reflect this. This needs to be reflected in both the language of any Strategic Framework document and in any ensuing Implementation Plan.

We note some of the documentation shared with us in recent days refers to digital health exclusively, and in other documents a much more inclusive term is used – namely, 'digital health and social care'. For us in Care Alliance Ireland, the latter terminology better reflects the reality of caring for a family member on a day-to-day basis. Such terminology also reflects the vision of SláinteCare, and the reality of life, in that most care work, either paid or unpaid, is more accurately described as 'social care' not 'hospital/medical centric care.'

SláinteCare also positions integrated care at the heart of future health and social care provision and places a greater focus on health promotion, the prevention of ill health and

¹ <https://www.carealliance.ie/OnlineFamilyCarerSupportGroup>

² <https://naswpress.org/product/53673/social-work-in-an-online-world>

overall wellbeing. These aspects of health care are where future additional funding will increasingly be allocated to.

To exclude the term 'social care' in the framework document seriously risks moving forward with a framework too narrow in focus, and in doing so risk its various stakeholders not valuing, funding, or indeed understanding, the potential that exists for eHealth within the social care/wellbeing realm.

The connection in Ireland between the traditional medical health system, and the provision of social care is relatively strong. This makes it easier to justify the inclusion of social care in the language of the overall framework.

In addition, consistency of terminology across documentation is required ensure clarity as to the critical elements of the eHealth plan Framework and subsequent Implementation Plan. There are many further policy documents that guide aspects of health and social care in Ireland, and all of these must be consistent in their approach, and not contradictory in any way.

For these reasons, and to ensure that any future implementation is inclusive of these aspects, we are firmly of the view that the framework document needs to be called

"Digital Health and Social Care Strategic Framework for Ireland 2023-2030".

2) Examples of Low-Cost Innovative Health and Wellbeing Interventions

To demonstrate both the potential of these interventions that fall more on the social care side of eHealth, we now provide examples of existing and embryonic practices to illustrate the true potential of such services:

- The Seamlesscare app being developed by Dr. Aviva Cohen/UCD to support family carers communicate with those who are non-verbal³.
- The Adult Autism Practice⁴ – who deliver full adult autism assessments online.
- Turn2me.ie⁵ who are delivering online mental health and counselling services.
- Happy Healthy Mind⁶ who are delivering virtual wellness and mind-fullness interventions.
- Care Alliance Ireland's own Online Family Carer Support Project⁷.

³ <https://seamlesscare.ie/>

⁴ <https://www.adultautism.ie/>

⁵ <https://turn2me.ie/>

⁶ <https://www.happyhealthymind.com/>

⁷ <https://www.carealliance.ie/OnlineFamilyCarerSupportGroup>

- The micro-credential course on Digital Technologies In Human Services being delivered in Trinity College Dublin⁸.

Such projects can act as exemplars for the roll out of other virtual services/supports with comparably little financial outlay.

From our own experience in the developing of the aforementioned Online Family Carer Support Project, online service delivery has the potential to reach much more people, at a significantly lower unit cost.

The examples of online delivery that we have just alluded to above, are the types of interventions that are accessible, simple to use and low cost. No €800m bill. No waiting to see how an EHR works in the new Childrens Hospital. No 10-to-20-year timeframe to deliver.

Face-to-face services cannot and should not be replaced entirely by virtual/online ones. To do so would exclude many service users who experience digital exclusion for reasons such as cost, availability of reliable, strong internet connection and lack of experience and training. However, where it is possible, across the community health/wellbeing space, it can represent a real opportunity to address some of the geographical issues that can impede access, enhance client retention and save both clients and practitioners time.

3) Securing Capital Funding alongside Effecting Cultural Change

We acknowledge that the roll out of a comprehensive suite of ICT tools, primarily for Electronic Health Records (EHR) will entail significant financial outlay, and will mostly be secured through capital allocations. We note the 2018 cost of estimate for EHR of between €609-€824m and the likely 10-20 year timeframe for its implementation.

However, the Framework should not be focused exclusively on securing access to capital funds. The framework and its implementation plan needs to be ambitious in also effecting cultural change in how services are delivered now, not in ten years' time. Securing funds will not necessarily lead to culture change.

Addressing the current real and enduring operational roadblocks to the deployment and use of existing technology have the potential to be easy wins and catch the low hanging fruit as it were, in the day-to-day operations of HSE services. We appreciate that on the face of it, the digital implementation of operational issues within the health and social care sector may not immediately be seen as part of 'eHealth', however we would argue that digital services which are part of the sector, and which those of us providing those

⁸ <https://www.tcd.ie/courses/microcredentials/by-school/micro-credentials---swsp/digital-technologies-in-human-services---micro-credential/>

service must operate under, do fall under this remit. We now provide some real world operational examples;

- HSE Administered National Lottery Application Processes
 - a. There is currently no consistency in how grant applications are received across HSE Community Health Offices (CHO's). Some require postal applications, some receive these digitally.
 - b. In addition, many CHO's will not accept digital signatures as standard, requiring significant delays and complications in making applications.
 - c. There is no facility for providers of virtual and by association national, services, to apply for funds.
 - d. We appreciate that these may change with the rollout of the Regional Health Authorities in the future, however it is vital that all systems within the DoH and HSE are consistent and modern in their approach to managing such funding schemes.
- The InterRAI Care/Carer assessment tool
 - a. This project, now almost 15 years old, has moved forward at a snails' pace with significant delays and roadblocks experienced in the development and pilot stages.
 - b. Any new Framework and associated Implementation Plan that does not actively and honestly learn from this case study risks making the same mistakes again into the future.

4) Questions on Governance Arrangements

To help us understand the landscape, we would welcome details of the governance arrangements in respect of progressing this framework. To that end we have some questions, detailed below.

- 1) What will be the role of eHealth Ireland (HSE)? Is it exclusively operations or does this team have a role in developing the Framework and the Implementation Plan?
- 2) What is the status of the six Change and Innovation Networks currently in place within the HSE? How will their work be informed by any future Framework/Implementation Plan? What will the role of the various National Directors of Change and Innovation be?
- 3) What is the status of the Irish Digital Health Leadership Steering Group?
- 4) What is the status of the Healthcare 4.0 Innovation Strategy?
- 5) What will the role of the Director of Digital Transformation and Open Innovation be?

7) Who sits on the newly established 'Technology and Transformation Committee' and what are its terms of Reference?

Responding to the Three Questions Posed

Q. 1) What are your priorities in terms of digital health right now?

- A policy that specifically includes social care, wellbeing, health promotion, and ambitious delivery of online support interventions with proven efficacy
- A funding approach that prioritises new resourcing for vulnerable and geographically isolated communities to a range of support interventions, most particularly for family carers who often can't travel due to their caring responsibilities
- A culture within both the HSE and the organisations that it funds that rewards the innovative and safe use of technology
- A governance system, steering the policy and implementation plan, that includes meaningful involvement by a range of stakeholders, and that critically includes those with an understanding of and expertise in well-being and virtual delivery.

Q.2) What are your views on the proposed Framework and Principles outlines?

We welcome the development of such a framework.

In particular, we welcome *Principle 1; Patient as an Empowered Partner*. For this to be meaningful in the long-term however, we ask that you look at the draft Patient Voice Partner Policy recently shared by the Department of Health. You will likely be aware of the major criticisms recently levelled by NGO's including ourselves⁹, about this draft policy. We have serious misgivings about the consultation process within the development of that policy.

Given that we have only recently come to know about this consultation process on eHealth, those misgivings remain with respect to such processes. We are however pleased to be involved at this relatively late stage. We look forward to a significantly revised further draft, that will properly reflect the values of public and patient involvement.

Regarding the one pager shared with us at the May 16th meeting, on slide 9, this would benefit from a reference made to access. For example, under proposed Principle 6: Digital Service Developments and Innovation, we suggest adding accessible, to read 'Our services are **accessible**, agile etc...'

⁹ https://www.carealliance.ie/userfiles/files/CAI_PatientVoices_Submission_Additional.pdf; https://www.ipposi.ie/wp-content/uploads/2023/03/2023-02_PVP-Policy_IPPOSI-Consultation-Response-to-Survey_FINAL.pdf

Finally, one ask is that in more detailed documents, and any implementation plan, that the term patient is defined and expanded to include 'family supporter'.

Q. 3) What do you think a successful/better digital health system looks like by 2030?

We in Care Alliance Ireland are firmly convinced that digital innovations are the future of not just physical health, but also mental and social well-being. All major health and social care policies in Ireland have at their heart a commitment to better health outcomes for patients and their families.

A digital health system must not be confined solely to creating linkages between physical health providers, although that is important. It must not be solely concerned with improving treatment outcomes or indeed creating cost savings, although these will follow.

The key to a successful digital health system in Ireland is that it is developed to value health and social care equally, involving patients and carers at every step of design and delivery, and one which is mindful and inclusive of intersectional issues within the health system. In line with Sláintecare, Healthy Ireland and other relevant policies, prevention and early access to appropriate supports is vital. The advances made, most particularly in social care and mental health support delivery, throughout the Covid19 pandemic, must not be allowed to stall. Many service providers in the NGO sector have developed ways of working digitally to provide supports. Over Covid19 many of these supports were ad-hoc and provided under a time of significant stress, however they can be used as exemplars of how services can be developed to be available online, as appropriate.

Digital health cannot, and should not, wholly replace traditional front-line face-to-face services. Digital literacy in Ireland is relatively high, however older people and those for whom English is not their first language can be intimidated by the prospect of accessing health and social care online. Online and digital services in this respect must be provided as accessibly as possible. For some, digital health is wholly appropriate and can make their experiences of the health system much easier and accessible. For others it will not be.

Conclusion

We are pleased to be able to make this submission with regards the development of an updated Digital Health and Social Care Strategic Framework for Ireland 2023-2030.

We understand that there are many aspects to the development of such a policy, and significant concerns regarding funding and implementation of the Strategy.

However, we believe that it is vital that any strategy for digital/ eHealth in Ireland takes a long-term, holistic view of health and social care together. There are many aspects to health, as acknowledged within Sláintecare, Healthy Ireland, Sharing the Vision and other

existing policy documents which guide the delivery of health and social care in Ireland. Any eHealth strategy must be cognisant of the potential of digital solutions not just to improve day-to-day medical health provision, but also to look to improve the health and wellbeing of the population, in both a preventative and responsive stance.

We look forward to further collaboration with the Department and the HSE in this matter.

About Care Alliance Ireland

Care Alliance Ireland is the National Network of Voluntary Organisations supporting family carers. Our vision is that the role of family carers is fully recognised and valued by society in Ireland. We exist to enhance the quality of life for family carers. We work with organisations to provide better information and supports to family carers. We provide them with opportunities to collaborate on initiatives including National Carers Week, a multi-agency and multi-disciplinary Family Carer Research Group, and joint policy submissions. We deliver a number of carer specific projects; namely an Online Family Carer Support Project and a Back to Work Project (Re-Emerge).

There are in the region of 500,000 family carers in the Republic of Ireland. Family carer support is provided by a number of organisations, including those dedicated solely to carer support and others who support carers as part of their response to individuals with specific conditions. We work with our 90+ member organisations and other agencies to support them in their work with family carers.

Our legitimacy derives in part from our membership base which includes a wide range of organisations currently providing services to Ireland's family carers. Our membership is comprised of both large and small, regional and national organisations.

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