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RESEARCH IN PROGRESS PAPER

TITLE

Children and Young People's Mental Health Services
Referral Innovation. Co-design and validation
methodology

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Children and Young People's Mental Health Services Referral Innovation. Co-design and validation methodology

Abstract

Children and young people's mental health services (CYPMHS) at Liverpool and Sefton Clinical Commissioning Groups referrals were paper-based. Paper-based referrals are inefficient and generate delays between appointments, which affect negatively on children and young people's mental health outcomes. Under a pilot-scale project funded by NHS England and with initial support from NHSX, Alder Hey Children's NHS Foundation Trust co-created with partner agencies the "CYP as One" to improve and digitally innovate the current mental health services provided to children and young people across Liverpool and Sefton region. "CYP as One" was created to improve the user flow for the children, young people, families and carers, as well as make the process easier and better for the teams that support them. This paper provides a reflective and critical analysis of the "CYP as One" platform co-creation and validation methodology. The innovation platform was launched in May 2021 and, currently, the authors are gathering real-world data on the innovation platform usage to validate the innovation claimed health and economic outcomes. It is anticipated that "CYP as One" will improve experience, communication and access to information from the young people themselves, their families and wider stakeholders. In addition, there is an expectation of reduced waiting times and "did not attend" cancellations and other benefits identified through costs and clinical time.

Keywords: Children and young people's mental health services (CYPMHS); Health Innovation; Living Lab; Real-world Validation; eHealth

Introduction

Problem: Children and young people's mental health services (CYPMHS) at Liverpool and Sefton Clinical Commissioning Groups referrals were paper-based. Paper-based referrals are inefficient and generate delays between appointments, which affect negatively on children and young people's (CYP) mental health outcomes.

Solution: Under a pilot-scale project funded by NHS England and with initial support from NHSX, Alder Hey Children's NHS Foundation Trust co-created with partner agencies the "CYP as One" to improve and digitally innovate the current mental health services provided to children and young people across Liverpool and Sefton region. The "CYP as One" project created a web-based platform (hereafter innovation) for a single data entry point for referral and appointment bookings which can be accessed and updated by all relevant agencies thus avoiding duplication and multiple data entries. Lastly, the platform provides access to the resources that children, young people and their families have said would be beneficial on the co-design phase. This has resulted in a fundamental change to how the referral system is structured, for what it is believed to be extremely beneficial for child, young people, their families but also all that are involved.

Aim: "CYP as One" was created to improve the user flow for the children and young people as well as make the process easier and better for the teams that support them.

Methodology: This paper provided a reflective and critical analysis of the "CYP as One" platform co-creation and validation methodology. The innovation was launched in May 2021 and, currently, the authors are gathering real-world data on the innovation usage to validate the innovation claimed health and economic outcomes.

Background Evidence

As the Children's Commissioner, Anne Longfield, pointed out in her recent report "Access to support remains the biggest issue for children's mental health services" (Childrens Commissioner, 2020, p2). This view is founded on research (Childrens Commissioner, 2018) about the difficulties faced by CYP in accessing CYPMHS services. The main findings of that research revealed that

- Of more than 338,000 children referred to CAMHS in the study year, less than a third (31%) received treatment within the year.
- Another 37% were not accepted into treatment or discharged after an assessment appointment, and 32% were still on waiting lists at the end of the year.
- Less than 3% of children in England accessed CAMHS in the study year, a small fraction of those who need help.

This evidence points to an unmet need for CYP compounded by difficulties in accessing services. And while the situation is improving over recent years, there are still barriers to access. One of these hurdles is the complexity of the current CYPMHS referral systems across the country, some of which are cumbersome and multi-layered. Streamlining and simplifying this point of access through

integrated digital technology would be a helpful addition to ensure that CYP receive the help they need. As Anne Longfield also comments “getting through that front door is an ordeal for too many”.

Methodology

There is an increasing drive to develop innovative and cost-effective strategies that focus on improving the quality of care. These innovative approaches will only work effectively if they meet real needs. Bearing this in mind, the Centre for Collaborative Innovation in Dementia works in partnership with stakeholders provides an open environment in which to innovate and validate potential solutions to the real-life challenges of the health and social systems (Smith, 2015; Smith & Simkhada, 2019). The Centre for Collaborative Innovation in Dementia is an accredited health Living Lab – the European Network of Living Labs (ENoLL).

The innovation was co-designed using a living lab approach led by the Alder Hey Children’s foundation trust and it will be validated by the Centre for Collaborative Innovation in Dementia using an innovative methodology entitle real-world validation (RWV).

Living Lab – innovation co-creation

“CYP as One” was co-created utilising a user-centred, research design methodology, putting the children and young people, as well as their families, at the forefront of the project. Twenty-six children and young people, thirty-one parents, and thirty-two health professionals formed the Open Innovation group.

Participants were recruited following response to a call via social media or by invitation at planned forum events. Additionally, already established workshops and focus groups were contacted and invited to participate. Further information and consent forms were sent to interested participants.

The project started at the end of January 2020, and the innovation was launched in May 2021. The innovation went through five iterations, which are described in detail below. The launched product was iteration number six.

The original deliverables of the project were:

- Scoped digital front door concept for the CAMHS Partnership Offer to improve access to information and services available.
- Development of single or connected platforms & digital engagement tools from pre-referral to post-treatment, ensuring cross-communication for the single patient.
- Prototype digital referrals from partners and self-referral – via a single platform.
- Enable Digital signposting and referrals to social prescribing, resources for self-help and/or wider CAMHS Partnership.
- Digital patient appointment booking, allowing SPA staff and patients to book appointments with at least 1 service provider partner as well as patients to quickly (re)book an appointment.

The co-creation process can be divided as follows:

- **Paper prototype (iteration 1)**

Drop-in sessions with Alder Hey Clinicians (5) and Bernardo's staff (2) to validate if what was needed was clinically necessary. The co-design team aimed to also involve children and young people and their families. However, this phase coincides with the COVID-19 pandemic and it was decided to delay these groups' involvement. Testing conducted between 13-19th March 2020.

- **NHS Prototype version 1 (iteration 2)**

Interviews conducted with GP's (2) and partner organisation staff members (2). From these interviews, it became apparent that there were fundamental issues with the prototype that needed changing. Testing conducted between 8th and 15th April 2020.

- **NHS Prototype version 2 (iteration 3)**

Interviews conducted with health professionals (2), parents (6) and CYP (2). Interviews conducted between 12th May and 7th July 2020. The team put a lot of time and resources to engage further with CYP and their families, however, engagement during the pandemic was hard to reach, which is a limitation acknowledged throughout the co-creation process.

- **Mindwave version 1 (iteration 4)**

Two workshops conducted with CYP with five participants on the 1st November 2020, and six participants on the 18th November 2020. Two workshops conducted with parents with six participants on the 11th November 2020, and seven participants on the 17th November 2020. In total, eleven CYP and twelve parents were consulted on the co-design of iteration 4.

- **Mindwave version 2 (iteration 5)**

Two focus groups were conducted with health professionals with twelve participants on the 16th February and nine participants on the 17th February 2021. Further, two focus groups were conducted with parents with twelve participants on the 22nd February, and seven on the 24th February 2021. Last but not least, three focus groups were conducted with CYP with six participants on the 17th February, five participants on the 22nd February, and two participants on the 24th February 2021. In total, twenty-one health professionals, nineteen parents, and thirteen CYP were consulted on the co-design of iteration 5.

Real-world Validation – innovation validation

RWV is an innovative methodology that uses real-world data (e.g. data captured by mobile devices or wearables usage) to determine, in a non-controlled environment (in the real-world), the effectiveness, and the outcomes to patients, staff and the health economy, of health innovation (Ganga, 2021). The value of real-world systematised information has been gradually recognised by health research more broadly. Real-World Data (RWD) is being increasingly used to the understanding of health innovations. When captured and analysed, RWD produces the Real-World Evidence (RWE) that underpins the economic case for innovative intervention in the health and social care systems. Why use this methodology to validate "CYP as One"? The use of computers, mobile devices, wearables, and other

biosensors gather and store huge amounts of health-related data has been rapidly accelerating. This data holds the potential to facilitate the understanding of the real-life impact of an innovation.

The innovation real-world validation will comprise three work packages (WP) across 7 months:

1. WP 1 – RESEARCH ETHICS AND GOVERNANCE

Establishing the project governance, including gaining ethical approval, and recruitment of a research assistant.

2. WP 2 – REAL-WORLD VALIDATION

2.1 Rapid literature review – a rapid, non-systematic literature review using standardised resources (PubMed, MEDLINE etc.) - explore existing health agency and service user data sharing arrangements, particularly those in the UK.

2.2 Real-world validation

- i. **Project aim** –validate the "CYP as One" data platform.
- ii. **Innovation's value proposition** – effectiveness measures and health outcomes against which the innovation's impact will be measured.
- iii. **Data capture and analysis** – Real-World Evidence (RWE) of the innovation on pre-defined outcomes. 20 service users and 20 service providers will be recruited to the project.
- iv. **In-market validation protocol design.**

WP 3 – Dissemination

3.1 Project reporting –during month 6 when findings and recommendations will be proposed

3.2. Journal article drafting –share the methodology, findings and conclusions of the health via a 3* journal article (e.g. BMJ Innovation).

Concludng remarks

It is anticipated that "CYP as One" will improve experience, communication and access to information from the young people themselves, their families and wider stakeholders. Benefits to flow from this work are

- one streamlined referral pathway for users for multiple mental health services over the Liverpool and Sefton area so they do not have to give the same information to lots of different services.
- ability to track referral so that the CYP, family or professional is aware of where their referral is up to
- decreasing administrative time for staff in the mental health services teams to allow more time to be spent supporting direct patient care
- reduced errors in transcription of referral details due to automation
- improved referral experience by referrer

- improved access to mental health services and support

In addition, there is an expectation of reduced waiting times and "was not bought" cancellations and other benefits identified through costs and clinical time. These benefits are to be validated by the implementation of the RWV protocol presented in the previous section.

References

Childrens Commissioner (2020). The state of children's mental health services January 2020 <https://www.childrenscommissioner.gov.uk/wp-content/uploads/2020/01/cco-the-state-of-childrens-mental-health-services.pdf> (accessed 16 June 2021)

Childrens Commisisoner (2018). Children's mental health briefing A briefing by the Office of the Children's Commissioner for England November 2018 <https://www.childrenscommissioner.gov.uk/wp-content/uploads/2019/02/childrens-mental-health-briefing-nov-2018.pdf> (accessed 16 June 2021)

Ganga, R. (2021, 07 22). Explaining Real-world validation. Retrieved 08 17, 2021, from <https://lcrhealthmatters.com/explaining-real-world-validation/>

Smith, G. (2015). Remembering to remember: the living lab approach to meeting the everyday challenges of people living with dementia. In D. Bruno, *The Preservation of Memory* (pp. 184-195). East Sussex: Psychology Press.

Smith, G., & Simkhada, B. (2019). Co-creating the living well with dementia message. *Issues in mental health nursing*, 40(9), 825-826. doi:10.1080/01612840.2018.1524530