

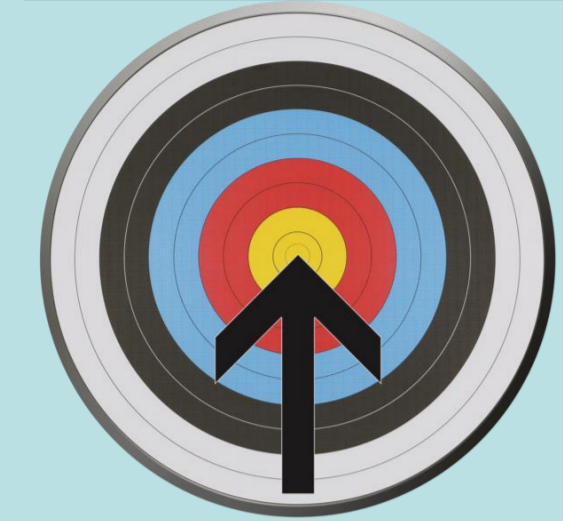
Virtual consultations for people with learning disabilities, their families and healthcare providers: A co-design study to aid implementation in everyday practice. A Study Proposal/ Early-Stage Research

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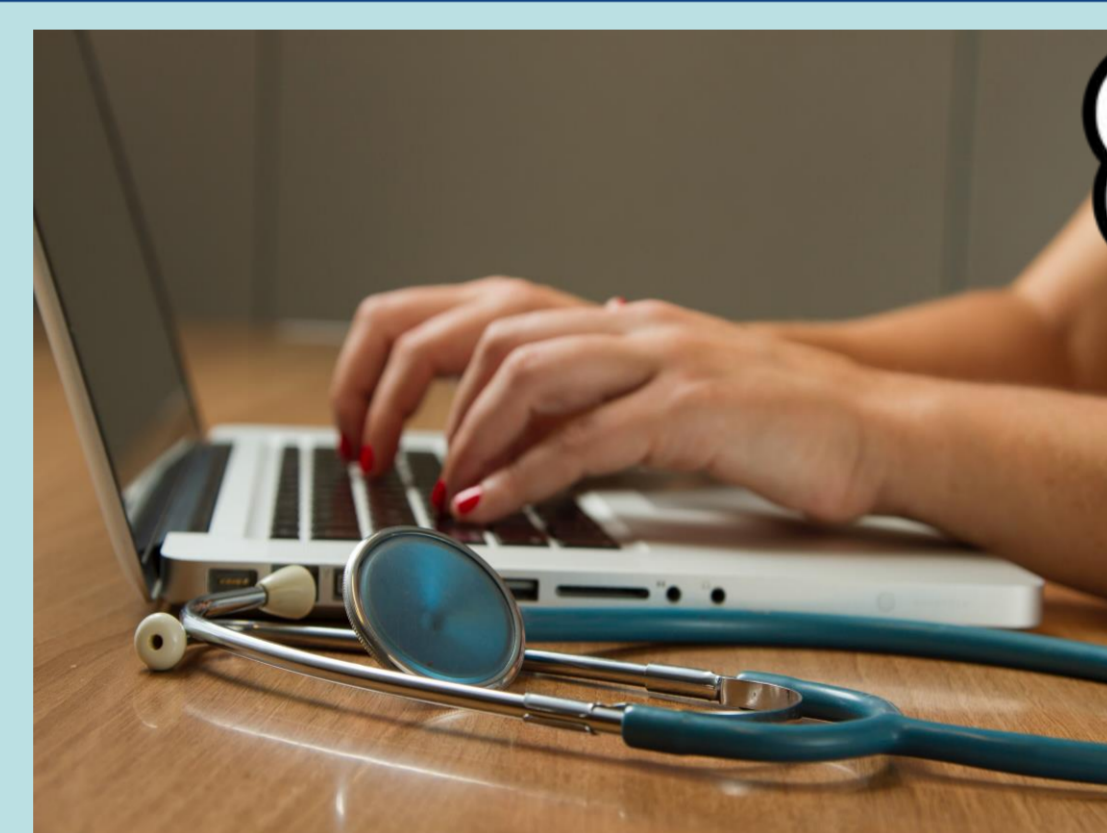
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Aim: To support People with Learning Disabilities (PwLDs) and their families to access and benefit from virtual consultations (VCs).

Background:

- Virtual consultations (VCs) have been around for a while, but initial adoption was not high, and problematic.(1)
- Implementing VCs in primary care (via telephone/email/video) has been expedited in recent months, but they can widen healthcare inequalities.(2)
- Implementation at pace due to COVID-19 means there has been little time to reflect on practice or amend/develop evidence-based guidelines on the use of VC.
- Little is known about use of online health services for PwLDs.(3) What evidence exists shows the need to support accessibility for users, by exploring the needs and preferences of PwLD themselves and to develop better guidelines for use.(3-5)
- Some advantages of using VCs for service users include convenience (less travel/time), less need to negotiate environmental/physical barriers, timely support/reassurance.(6-7)
- However, specific concerns have been raised about VCs including potential variations in patient access, increased workload for healthcare professionals (HCPs), impact on quality & safety of communication (less information/visual cues), relational issues (rapport/trust) and lack of guidance for HCPs.(8-9)



Objectives:

- 1.To understand experiences and views of PwLD, and their families/support workers of accessing and interacting with HCPs using VCs including non-user views.
- 2.To explore HCPs views and experiences of delivering care virtually with PwLD/families to understand opportunities, challenges and approaches to risk mitigation.
- 3.To bring PwLD, their families and HCPs together in a co-design process to reflect on findings from the (above) objectives and establish improvement priority areas.
- 4.To co-design tangible resources, such as best-practice guidance, training and support materials to positively change VC experiences and practice.

Methods & Stages of Work

This study will use an experience-based co-design (EBCD) approach.

Stage 1: - Observations and Interviews

- Rapid review of current guidance on VC use/delivery for PwLD.
- Filmed/recorded VC observations with PwLD/families & HCPs (n=13).
- Qualitative interviews (with above participants) (n=39).
- Plus, telephone interviews with non-users (n=6).

Stage 2: - Film Production, Priority and Co-design Events

- Production of a narrative film using PwLD/families interview material. Presentation of film at a priority setting online event with PwLD/families to identify development areas.
- A separate priority setting event will be hosted for HCPs.
- A joint co-design event where support materials will be co-created.

Stage 3: - Production of Supportive Materials & Feedback

- Development and feedback of co-created support materials.

Setting: Primary and community care. HCPs include GPs, Nurses & Allied Health Care Professionals.



Open Research:

Steps we have/will take to ensure our work meets Open Research standards.

1. Our work is collaborative and inclusive.

- Our research team includes experts by experience and community collaborators.
- Our use of accessible communication in all research documents.
- Our choice of Experience-Based Co-Design as an action research method.
- Our use of multimedia e.g. touchpoint film.

2. Transparency.

- We will ensure transparent reporting of our research design and methods.

3. Our work is discoverable and publicly available.

- We will adopt standard identifiers (such as ORCID and DOIs) to aid discoverability.
- We will aim for open access publications.
- We will use a variety of ways to connect with non-academic interested parties including presentations, talks, social media, blogs and articles for non-academic publications (such as Community Care).
- We will have a dedicated website.
- All resources will be publicly available and reusable.

4. We have a robust and comprehensive data management plan.



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Images: Photosymbol, National Cancer Institute, Pawel Czerwinski/Unsplash, easy-on-the-l - Leeds and York Partnership NHS Foundation Trust

Relevance & Impact:

- Potential to improve digital inclusion, access to and integration of care for PwLDs and their families.
- Improve quality of interactions between HCP & PwLD/families.
- Additional way to provide daily/annual care (Health Checks).
- Greater convenience in attending health appointments.
- Offers further innovative opportunities to improve the health care experience for PwLD and their families.



Our Research Collaborators:

• Partner Organisations:

- halow
- Surrey Coalition for Disabled People

Our Experts-by-Experience (EbE) Group

- Educators: Angela Kubacki (St. George's) & Susan Brooks (UoS)
- Primary Care GP Contacts & Project Advisory Group



References: ¹Greenhalgh et al 2016 (doi: 10.1136/bmjopen-2015-009388), ²Mold et al 2021 (doi:10.1136/bmjhci-2020-100256), ³Vázquez 2018 (doi:10.3389/fpsyg.2018.02323), ⁴Haymes et al 2015 (doi: 10.3109/17518423.2013.850750), ⁵Oudshoorn 2018 (doi: 10.1111/jar.12758), ⁶Donaghy et al 2018 (doi: 10.3399/bjgp19X704141), ⁷Vimalananda 2015 (doi: 10.1177/1357633X15582108) ⁸Mold et al 2019 (doi: 10.2196/13042), ⁹Hammersley et al 2019 (doi:10.3399/bjgp19X704573)