

My Health Guide: A trial of a tablet app to support people with learning disabilities

Submission date 02/11/2016	Recruitment status No longer recruiting	☐ Prospectively registered
		☐ Protocol
Registration date 18/11/2016	Overall study status Completed	☐ Statistical analysis plan
		☐ Results
Last Edited 30/10/2019	Condition category Mental and Behavioural Disorders	☐ Individual participant data
		☐ Record updated in last year

Plain English summary of protocol

Background and study aims

People with learning disabilities experience poor health in comparison to the general population. This study is trialing a computer tablet based app designed for adults with learning disabilities to enable information sharing between them and health practitioners. The My Health Guide app is intended to empower people with learning disabilities and provide them with greater control, as well as providing people who support them with information to enable them to better understand and connect. It is hoped this will enable people with learning disabilities to play an active role in their healthcare, through receiving and sharing health related information, in a range of formats appropriate to their communication needs and preferences. The aim of this study is to find out information about the contexts in which people with learning disabilities (and their supporters) are able to make successful use of My Health Guide and the usability of the app.

Who can participate?

Adults with learning disabilities who are users to the NHS learning disability service in Hull and the East Riding of Yorkshire and organisations working with them.

What does the study involve?

After agreeing to be part of the study, participants are given access to the App for approximately three months before they are asked about their experiences of using it. Participants are also able to keep the computer tablet they have been issued with and access to the App once the study has finished. A small number of participants are also invited to take part in interviews, focus groups or case studies as well as completing the questionnaire.

What are the possible benefits and risks of participating?

Participants may benefit from an improved ability to explain their needs and concerns, understand how to act on advice given to them and to share information. There are no notable risks involved with participating.

Where is the study run from?

Townend Court, Learning Disability Service (UK)

When is the study starting and how long is it expected to run for?
September 2015 to December 2016

Who is funding the study?
Small Business Research Initiative for Healthcare (UK)

Who is the main contact?
Mrs Patricia Bailey
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Contact information

Type(s)
Public

Contact name
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Additional identifiers

Integrated Research Application System (IRAS)
194840

Protocol serial number
30775, IRAS 194840

Study information

Scientific Title
My Health Guide – A non-randomised trial of a tablet application designed to support people with learning disabilities

Study objectives
The aim of the study is to:

1. Understand the contexts in which people with learning disabilities (and their supporters) are able to make successful use of My Health Guide, and achieve positive outcomes, as well as contexts which impair use
2. Measure the extent to which participants adopt My Health Guide as a consistent approach to the management of their health

Ethics approval required

Old ethics approval format

Ethics approval(s)

North East - Newcastle & North Tyneside 2 Research Ethics Committee, 10/02/2016, ref: 16/NE/0016

Study design

Non-randomised; Interventional; Design type: Process of Care, Education or Self-Management, Management of Care

Primary study design

Interventional

Study type(s)

Treatment

Health condition(s) or problem(s) studied

Specialty: Mental Health, Primary sub-specialty: Learning disorders; UKCRC code/ Disease: Mental Health/ Disorders of psychological development

Interventions

An overall sample size of 200 My Health Guide users is planned. Participants will be provided with access to the app following consent. After using the app for approximately 3 months, follow-up data will be collected in the participants' place of residence, or in some cases their place of work, as follows:

Questionnaire

Participants will be given a questionnaire to complete (duration approx. 30 mins) designed specifically for this trial.

Semi-structured interviews

Interviews (duration approx. 1 hour) with 15 people, selected using purposive sampling, will be conducted to gain an in-depth understanding of their experiences of using the app. The interview guide has been developed specifically for the trial.

Case Studies

Five in-depth case studies will be conducted (duration approx. 1 hour per person). Potential case study participants will be selected on the basis that they are frequent users of the My Health Guide app or are using it in especially interesting, creative or unexpected ways.

Focus Groups

Focus groups (duration approximately 2 hours per group), using a guide developed specifically for this study, will be conducted with healthcare practitioners and independent care providers to collect data about their views and experiences, since they will be key users of the My Health Guide app, alongside people with learning disabilities.

Participants will be able to keep their computer tablet and access to the app once the study has finished.

Intervention Type

Other

Primary outcome(s)

All outcome measures have been designed specifically for this study; no standard outcome measures are used and all are classed as primary outcomes.

1. Experience of using the My Health Guide app is measured using questionnaires, semi-structured interviews, case studies and focus groups in the participants' place of residence, or in some cases their place of work
2. Usage of the app is measured using the backend usage data automatically collected remotely by the software provider

Key secondary outcome(s)

No secondary outcome measures

Completion date

30/12/2016

Eligibility**Key inclusion criteria**

1. Aged over 18
2. People with learning disabilities who use the care planning process or who have a care plan in place
3. People with learning disabilities who are supported by named carers who implement the care planning process on their behalf, and who are not able to use My Health Guide themselves
4. People with learning disabilities living in settled accommodation

Participant type(s)

Patient

Healthy volunteers allowed

No

Age group

Adult

Lower age limit

18 years

Sex

All

Key exclusion criteria

1. Under the age of 18
2. Not providing consent to participate (or their consultee has not agreed to this)
3. People are not living in settled accommodation (this is due to concerns that the provision of the
may increase their vulnerability)

Date of first enrolment

01/02/2016

Date of final enrolment

15/11/2016

Locations

Countries of recruitment

United Kingdom

England

Study participating centre**Townend Court**

Learning Disability Service

Cottingham Road

Hull

United Kingdom

HU6 8QG

Sponsor information

Organisation

Maldaba Limited

Funder(s)

Funder type

Government

Funder Name

Small Business Research Initiative for Healthcare

Results and Publications

Individual participant data (IPD) sharing plan

Datasets will not be made available – this is due to reasons of confidentiality.

IPD sharing plan summary

Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
HRA research summary			28/06/2023	No	No