BSL-IAPT Research Project

Modelling BSL-IAPT and Standard IAPT accessed by Deaf people: Standard IAPT Services (NHS or non-NHS sites) Data Transfer STANDARD OPERATING PROCEDURE (SOP)

Version 1.2 – 16.03.16

TITLE: Modelling BSL-IAPT and Standard IAPT accessed by Deaf people: Standard IAPT Services (NHS or non-NHS sites) Data Transfer SOP
VERSION: 1.2 Date: 16.03.16
PURPOSE: To describe the process for transfer of pseudo-anonymised datasets from the service user database of each participating IAPT service to the BSL-IAPT Project research team based within the Social Research with Deaf People Research Group, School of Nursing, Midwifery and Social Work, University of Manchester.

If you have any queries please contact either the Chief Investigator, Professor Alys Young (email: [redacted]; phone [redacted]), the Trial Manager, Dr Katherine Rogers, (email: [redacted]) or the Research Assistant, Ms Claire Dodds (email: [redacted])

1) DEFINITIONS

BSL: British Sign Language

IAPT: Improving Access to Psychological Therapies

HSCIC: Health and Social Care Information Centre

BSL-IAPT Research Project (and Team) is the short name of a research study funded by the National Institute of Health Research Ref No. NIHR HS&DR 12/136/79 and run by the University of Manchester. The publically accessible

research summary is available on the funder's website (NIHR Evaluation, Trials and Studies) at http://www.nets.nihr.ac.uk/projects/hsdr/1213679 and the Project website is http://www.manchester.ac.uk/bsliaptevaluation.

Pseudo-anonymised is used in the context of the Project paperwork to mean a dataset which carries no personal information about patients that would allow them to be identified by individuals outside the Research Team and the IAPT service from which the dataset is derived i.e. the dataset is entirely anonymised with the exception of a field containing a unique patient identification number. This number conveys no personal patient information to the Research Team, but would allow them to query, for example, missing data with the IAPT service Team by reference to that number. This field will also be removed prior to statistical analysis.

Patient ID: As above, this is an identifier where each site allocates a number to each patient (this must not be the same as the NHS identification number) when they transfer the data to the Research Team.

Service ID: This is a code allocated to each site taking part in this study by the Research Team (for our records only). Please note that this is not the same identification number used by the NHS or by the Health and Social Care Information Centre (HSCIC) to identify a service.

NHS site: A NHS service provider.

Non-NHS site: a service provider who is offering IAPT on behalf of the NHS and/or commissioned to do so by a CCG. This provider may or may not be affiliated with a specific Trust.

2) PURPOSE

To describe the responsibilities and procedures associated with the extraction and transfer of a specified pseudo-anonymised dataset from the patient records system of each participating IAPT service to the BSL-IAPT Project Research Team based at the University of Manchester. This project-specific data transfer Standard Operating Procedure applies to, and should be followed by, all staff involved in this research

project in both the participating IAPT service team and the BSL-IAPT Research Team.

3) PROCEDURE

WHO

All service provider and research team staff who are responsible for and involved in the extraction and transfer of this specified dataset for the BSL-IAPT Project.

WHEN

This procedure should be followed at all times to ensure that ethical and clinical governance requirements are adhered to in the management of this data.

HOW

Governance requirements

NHS sites will have permission for data transfer following 'authorisation to commence' obtained by the research team with respect to the relevant R and D process for the Trust.

Non-NHS sites will be required to follow their own internal governance procedures to confirm authorisation for data transfer. These will vary between service providers and confirmation that they have been followed is required in written communication with the research team. The research team will initiate this confirmation with the site prior to data transfer.

Dataset identification and extraction

See attached documents [Standard IAPT service fields for data transfer v1.2 CLIENT REG TAB (09.03.16) and Standard IAPT service fields for data transfer v1.2 CLINICAL CONTACT TAB (09.03.16)]. These documents have been highlighted (in amber) to show the fields which are returned in the mandatory IAPT reporting to the HSCIC. The rest are collected and retained by the service provider under their service agreement with IAPT. This document was the guide for the extracted dataset provided

by BSL Healthy Minds to the BSL-IAPT Research Team in the previous study – the dataset which will be used for comparison with the datasets obtained through the current study. The fields that are requested for the data extraction are highlighted in lilac and exclude NHS number, date of birth and post code as well as other information that may identify the patient.

Each IAPT service is required to extract data from their IAPT patient management system on only their clients who are Deaf BSL users and have been referred to the service since 1st of January 2012. The clients must therefore be identified through their language use (i.e. BSL) rather than through the recording of them as being 'deaf' or 'hearing impaired'. As language is not a mandatory reporting field to the HSCIC, this information is stored in different ways between services. The following have been reported by services as possible routes to identifying eligible clients:

- Sub-field of the disability field 'hearing impaired' but note this does not necessarily imply BSL users in all cases
- Bespoke field about language use and/or interpreter booking that might identify BSL
- In a separate administration system used for interpreter booking, then cross-referenced with the IAPT patient management system
- Clients known by a member of staff who specialises in service provision to Deaf and/or other minority language groups
- Extraction of all clients who are recorded as deaf/hearing impaired through the disability field and then individual review of these records for identification of language use

For further bespoke advice and support on data extraction please contact the research team.

Data transfer

The designated BSL-IAPT research team member provides the named clinical contact in each IAPT service (this may be Clinical Lead, IT Lead, Service Manager – it varies between services) with a password-protected Excel template spreadsheet that matches

the fields detailed in the section above [Data extraction template for clients who are Deaf BSL users V1.2; which contain the same data fields as outlined in two PDF documents: Standard IAPT service fields for data transfer v1.2 CLIENT REG TAB (09.03.16) and Standard IAPT service fields for data transfer v1.2 CLINICAL CONTACT TAB (09.03.16)].

The clinical contact person contacts the BSL-IAPT research team by SMS to request the password to the spreadsheet. Once the spreadsheet is populated with data, the clinical contact transfers the file using the secure Zend To service approved by the University of Manchester. Background information is available at: https://zendto.manchester.ac.uk/ and https://zendto.manchester.ac.uk/about.php, but they can email the designated research team member who can then send them a 'Request a Drop-off' request which makes it straightforward for them to upload the file to the secure server.

Sites are also required to complete the Standard IAPT Data transfer record V1.2 (16.03.16) to as a record of their transfer of the data. This should be returned in either digital scanned format or by email in hard copy by post to the Trial Manager (Dr Katherine Rogers – contact details above).

Please contact the research team for any bespoke support required to complete this task.

NHS
National Institute for Health Research

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