Develop and Enhance the Care COordination for people with intellectual DisabilitiEs and multiple long term conditions.

Some people with learning disabilities have health problems that last a long time. The DECODE project wants to help people with learning disabilities have better healthcare.
Newsletter 01, July 2023

Left to right; Cecilia, Angela, Alison, Rania, Amy, Sarah, Emeka, Ashley, Thomas, Georgina, Akshika

DECODE Team (not all of us!)

With the DECODE team based across the UK (Loughborough, Leicester, London, Swansea and Nottingham), it's all too often an on-line meeting or e-mail discussion that brings us together, so it was lovely to meet up with some of the team, face to face, at a conference in Birmingham in the Spring.

Meet the DECODE team

Left to right; Alison, Sarah and Amy

DECODE activities -Spring 2023

So what have the DECODE team been up to:

- **Road-shows** - some of you may have seen us out and about in Leicestershire, publicising our project and encouraging people to take part. If you haven't got a DECODE stress ball or tote bag, come along to one of our future events.
- **Data activities** -Rania, Emeka and Akshika (Work Package 1 & 2) have been very busy working on one of two data sets -SAIL data (Wales GP and hospital health records), with the help of our PAP team (see below) and Swansea colleagues, Danielle and Ashley, reviewing records that fit the project criteria (over 18, with learning disabilities and multiple long-term health conditions), health conditions over time (for example; diabetes, asthma), and factors that may affect health (for example; smoking). No individuals are identified in the data. The team are also undertaking reviews to make sure that nothing is missed out and all data equally considered (no bias or mitigating circumstances).
- **Participant events** - After the project was given ethical approval by the NHS in March, we were finally able to start asking the public for help, talking to people with intellectual disabilities (ID), carers and health professionals (April to June):
    - Navjot - held group meetings with healthcare professionals asking them about what a good dashboard would look like (IT screen showing ID healthcare information to a GP or hospital worker).
    - Alison - held a group meeting with people with learning disabilities and their carers asking them what visual information would help them to understand healthcare information.

- Cecilia - has been meeting individuals with learning disabilities, carers, social care and healthcare professionals to better understand health issues and experiences.

More about DECODE

Left; Cecilia, Right, Sarah, Foreground, Amy

PPIE (Patient and Public Involvement and Engagement) and PAP (Professional Advisory Panel)

None of our activities would be well informed without the dedication of out wonderful PPIE groups, led by Sarah and Amy, and PAP group, led by Satheesh. They are with us every step of the way, guiding our preparations, advising us on our website, workshop content, data definitions and so much more. Many thanks to each and every one of them for sticking with us!

Summer/Autumn 2023

A busy and exciting period ahead ahead of us:

- the **second of our two data sets** (CPRD - England GP and hospital health records) is due to arrive in September, so the (WP1 & 2) teams are getting ready, so work can commence straight away.
- Further research with our participants. **Group meetings and interviews** in September
- **Analysis and preliminary results discussions**. The team are excited to be getting together in the Autumn to discuss the **outcomes, progress, plans and impact**. When we have project news to share with the wider world, we want to make sure it's heard.
- A **DECODE video** taking place, to demonstrate what being involved in the project as a participant is all about - watch this space!

Interested in taking part - enquiry form

DECODE is a research project, under the AIM (AI and Mutliple long-term conditions) umbrella funded by the National Institute for Health and Care Research (NIHR).

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View the DECODE websites