CYGNUS: A digital brain health platform for improving dementia outcomes

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Many people with dementia are poorly served by the healthcare system.

Drug availability is very limited and none have been shown to change the course of the most common causes of dementia e.g. Alzheimer’s disease.

Non-drug treatments are often supported by limited evidence and not widely available.

Many treatment strategies are moving to earlier in the disease (e.g. Dementia Platform UK, European Prevention Alzheimer's Disease Consortium), and are highly “enriched” populations that are not representative of the “real world”.

We need new approaches to developing treatments and interventions that focus on outcomes that matter to patients and their carers.
New Forms Of Collaboration

Diagram: Four interconnected circles labeled Industry, NHS, Academia, and Research Charities, with a central figure labeled Patients and a label for Data and eHealth.
Northern Health Science Alliance

To maximize the impact of the health science research and to provide a go-to center for healthcare companies we have created the Northern Health Science Alliance (NHSA), a collaboration across eight of England's great cities across a population of 15m people.
Innovation Pathway

The Northern Powerhouse has an integrated innovation pathway from basic research, to clinical validation and market access. Through the Northern Powerhouse you are able to access major expertise in agritech, bio manufacturing, precision medicine, ageing and population health.
The Cygnus Project

- Three year project funded by Innovate UK, ends March 2018
  - IXICO
  - The Northern Health Science Alliance
  - Manchester Mental Health and Social Care Trust

- Grant partners are:
  - Tees, Esk and Wear Valleys NHS Foundation Trust
  - Northumberland, Tyne & Wear NHS Foundation Trust
  - Mersey Care NHS Trust

- Recently joined the high profile Dementias Platform UK (DPUK)
Aims of the Cygnus study

- **Collecting real world data at memory services and from patients and carers**
  - Standardized longitudinal real world data including outcomes from a large sample of symptomatic patients presenting with memory concerns and their carers, post-diagnosis collection of longitudinal data over 1 year
  - Validate methods and technology for capturing, integrating and analysing data and make it actionable for stakeholders (researchers, pharma, providers and commissioners)
  - Enable prospective evaluation of cost of care in the NHS and evaluate the cost effectiveness of digital interventions
A validated, standardized dataset will be collected over a one year follow up period and includes:

- Demographic
- Health and clinical history
- Clinical assessments (as performed by the MAS)
- ICHOM dementia standard dataset
- Post-diagnostic interventions
- Medical events information

Two sub-studies to evaluate data collect from mobile and wearable devices:

- Collection of patient and carer report outcomes from mhealth applications at home on a weekly basis
- Collection of continuous activity and sleep data using a wearable device over a 12 week period
Cohort Population, Size and Recruiting Centres

People with cognitive impairment or possible dementia, referred to a MAS by their GP

Partner, family member or close friend of the study participant

- REC and HRA approvals granted
- To date 28 participants have been recruited across the 4 study sites

Study Partner

GP → MAS → Study Participant

Northumberland, Tyne & Wear NHS Foundation Trust
Tees, Esk and Wear Valleys NHS Foundation Trust
Mersey Care NHS Trust
Manchester Mental Health and Social Care Trust
Cygnus is about Building Capability

- Define a better way of studying people with memory problems in the “real world”
- Set a new standard for evaluating treatments and care that have potential to impact patient outcomes and assess impact on costs to the NHS and society
- Evaluate new ways of collecting data via sub-studies looking at “digital biomarkers”
  - Technology used by study participants and their carers to track progress
  - Potentially more sensitive ways of assessing whether treatments make a meaningful difference
- A platform to build on:
  - Cygnus participants can be approached for new studies e.g. to assess new drug or non-drug treatments
- At the heart of UK dementia research by linking to the Dementia Platform UK
Thank you for your attention