

# CAPTURING THE EXPERIENCE OF PEOPLE WITH DEMENTIA

**SOCIAL SENSE LTD. AND HITCH WANT TO WORK IN PARTNERSHIP WITH YOU TO BUILD A PLATFORM THAT WILL MEASURE IN REAL TIME, THE EXPERIENCE OF PEOPLE LIVING WITH DEMENTIA AND THOSE WHO CARE FOR THEM.**

## Dementia United



### OUR AIMS AND AMBITIONS:

“Our aim is to create something that focusses not on the dementia, but the person and those around them. We want to capture everything that is positive, for example friendships and achievements alongside thoughts, feelings and concerns.

People living with dementia tell us the importance of positive experiences of using local services, for example transport, shops and interactions with GPs and other professionals. Through this platform we have a real opportunity to better understand and improve these experiences across Greater Manchester.

We also want to provide an easier way for individuals to connect within their communities in meaningful ways, which we also know can significantly improve purpose and wellbeing.

Our shared ambition is to take this far beyond a measurement tool. We're driven most by the potential for our combined knowledge and technologies to significantly and measurably improve lives”.

Gary Lovatt  
Social Sense

There are around 540,000 carers of people with dementia in England. It is estimated that one in three people will care for a person with dementia in their lifetime. Half are employed and it's thought that some 66,000 people have already cut their working hours to care for a family member, whilst 50,000 people have left work altogether.

There is a considerable economic cost associated estimated at £23 billion a year, which is predicted to triple by 2040. This is more than the cost of cancer, heart disease and stroke.

In Greater Manchester (GM) there are approximately 30,000 people diagnosed as living with dementia making it a major priority to find new ways of supporting and improving the lives for those living with dementia.

“In 2016, Dementia was highlighted as one of the early Devolution priorities. Devolution gives us the freedom and flexibility to make decisions locally about the health and care of the 2.8 million residents living in the 10 boroughs that is Greater Manchester (GM).

Dementia United (DU) is the five-year transformation, support and development programme to build on the great work that is already taking place, alongside developing a campaign and platform for improvements. It will be delivered through key partnerships, listening to the voice of people living with dementia and those who care for them and offering the opportunity to have a 'big conversation' across GM.

We are delighted to be working in partnership with Social Sense on this unique, innovative project and understand better than ever the impact of living with dementia”.

Gaynah Butler, Quality Improvement Manager  
Dementia United

### BACKGROUND

Dementia is a growing challenge. As the population ages and people live for longer, it has become one of the most important health and care issues facing the world. In England it is estimated that around 676,000 people have dementia. In the whole of the UK, the number of people with dementia is estimated at 850,000.

## THE PROJECT

Our objective is to co-design, develop, and launch a platform that successfully measures the experiences of the various groups of individuals who are touched by dementia in Greater Manchester.

- Persons living with dementia
- Professional carers of those living with dementia
- Care giving family members
- Significant peers (close friends / non-care giving family members)

We began our process of consulting with the above groups in March 2019 and will continue to work closely with individuals and groups to ensure the best possible result.

## ABOUT THE BAROMETER

The feature ideas are currently evolving in response to the work we are doing with the above groups.

Some early ideas for we are exploring include:

- Creating a safe place to 'check in' for people to assess their current wellbeing, any notable changes and things that may help improve.
- Access to local dementia friendly activities according to the location and interest of the user.
- The ability to integrate information captured from other sources so that person remains at the centre.
- A schedule planner and activity log, which would be shared with carers and generate system prompts/reminders for key events.
- Goalsetting features that can be completed by users and/or those around them.
- Recording journals - for example gratitude, celebrating achievements, reflecting on time with family and friends.
- The ability to document and track notable changes as a result of professional and social experiences, for example transport, professional care, or family visits.



We are committing to this project to understand what it's like to live with dementia in Greater Manchester, what makes a good day and what gets in the way.

The intelligence we can gather from this platform will help us to achieve our ambition for Greater Manchester to be the best place to live with dementia”.

**Warren Heppolette | Executive Lead,  
Strategy & System Development  
Greater Manchester Health &  
Social Care Partnership**



## KEY MILESTONES:



**RESEARCH**



**DESIGN**



**DEVELOPMENT**



**LAUNCH**



**MAINTENANCE**

- Consultation and Scoping: Spring 2019
- Design and Development: June–December
- Testing: January–Feb
- Version 1 Launch: March 2020
- Modifications, maintenance and Rollout April 2020 to 2021.

**Would you like to be involved in this project?**

If you are a person living with dementia or caring for those who are, we'd really like to hear from you.

To get involved email [info@socialsense.co.uk](mailto:info@socialsense.co.uk) or call 0161 216 4080