

**Manchester
Metropolitan
University**

The evaluation of a mobile platform (Greater Moments) to support people with dementia and those around them.

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Dr Lorna Chesterton
Professor Anya Ahmed
Social Care and Social Work
Faculty of Health & Education

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Glossary of terms used in this report

Care-partner refers to a person who supports an individual who is living with dementia and does so in an unpaid capacity. The term care-partner has been widely adopted by those supporting people living with dementia, as it acknowledges that care-partners facilitate a negotiated care plan with the person with the condition, who remains central to all decision-making and care responsibilities.

Web Application (Web App) refers to an application program which is stored on a remote server and accessed through the Internet via a browser interface. A Web App can be accessed by smart phone, laptop or desktop computer.

Native application (Native App) refers to an application program that is developed for use on a particular platform or device. It can be downloaded from a digital distribution platform such as Apple's App Store or on Android via Google play.

The evaluation of a mobile platform (Greater Moments) to support people with dementia and those around them.

Executive Summary

Around 850,000 people in the UK are currently living with dementia (Alzheimer's Society, 2014) and approximately 540,000 people are acting as informal care-partners to someone with dementia (DoH, 2015). Over the last decade there has been a policy driven strategy to improve the quality of life and wellbeing for people living with dementia by improving societal awareness of dementia, and developing better dementia care services (DoH, 2015). The development of structured peer support, information networks, and the promotion of dementia friendly resources have been an identified goal of successive strategic policies (DoH, 2009; DoH, 2015; Duff, 2018; NICE, 2018) empowering people with dementia and their families to maintain social engagement and influence future service provision (DoH, 2012).

The *Greater Moments* Web App has been developed by Social Sense Ltd with funding support from Greater Manchester Health & Social Care Partnership. It is a live social platform that aims to measure and improve the quality of life for people living with dementia and those around them. Its features include real time recording of emotional wellbeing, a 'moments' journal and a person-centred social feed of activities, events and services that are happening locally or virtually. *The Greater Moments* Web App has the potential to bridge the long-held data gap between social and clinical support, giving users, service providers, and commissioners access to vital information about service provision, and gaps in service. As of July 2021, there were 147 Web App users, which included 28 people who are living with dementia, 59 unpaid care-partners and 60 people providing care and support professionally. It has also recruited 12 'champions' who will seek to improve engagement and recruitment of users moving forward. The Web App has to date identified 170 services/organisations across the GM region, ranging from dementia specific organisations such as 'The Lewy Body Society' to organisations providing services to the general public such as the 'National football Museum'. To date, 286 activities and events have been advertised on the Web App which have been both dementia specific, (such as an online event focusing on 'caring for someone with dementia') and events of general interest (such as 'Bolton food and drink festival' or 'The River city cruise').

In Late-June 2021, Dr Chesterton and Professor Ahmed from Manchester Metropolitan University were commissioned to undertake an evaluation of the 'Greater moments' digital platform, developed by Social Sense Ltd. This work utilised a mixed method approach and explored the overall efficacy of the Web App, and how it was being used by people who were living with dementia, care-partners and those providing care and support professionally. The Web App allowed users to record a journal entry, before

prompting them to enter an emotional wellbeing score, whilst also linking them to a person-centred social feed of activities, events and services that were happening geographically local, or online. It must be noted that the roll out of the Web App was severely impacted by the COVID-19 pandemic, as older people were advised by the UK Government (Gov.UK, 2020) to shield themselves, not leaving their houses or having physical contact with anyone outside their own household. For those living with dementia this meant that vital face-to-face support groups were cancelled, and visits to places or events, which were likely to stimulate interest and promote wellbeing could not go ahead. As statutory and third sector support networks, adapted to new online methods of service delivery, the Web App was able to provide links to virtual, online activities. In addition, the Web App was used to livestream a Christmas party for all users, networks, and participating care homes, which allowed valuable social contact and connectivity at what was a very emotional time.

As will be discussed in this report, the evaluation was severely impacted by the lack of data collected, which has obviously limited our findings, and generalisability of this work. However, the results offer useful benchmarks, to inform the next stage of the development, which is a native App, available free of charge, to download on the App Store and Andriod onto a smart phone or tablet. Key findings illustrate the benefits which the Web App has delivered for existing users, and the potential which will be realised in the next version. It is also acknowledged that an ORCHA review was carried out in January 2021 and, with a score of 71% found that the Web App demonstrated approved practice, with ORCHA supporting the next stage of development.

Key findings

- The Web App offers an opportunity to address the support needs for people living with dementia and their care partners through connectivity. The Web App does this by making them aware of local activities. Existing evidence suggests that increasing connectivity and creating networks can positively impact social isolation and increase wellbeing (NICE, 2018).
- The Web App offers a way to promote interaction and participation in events, organisations and venues, both in terms of signposting what is happening in the local area, and by giving feedback to services and others living with dementia. Research supports the need to improve information giving, in a timely manner for people living with dementia, to improve social engagement (NICE, 2018)
- The Web App allows people to keep journal-like entries, by recording 'moments' or 'happenings' in their everyday lives. This appears to offer some catharsis to users, by giving individuals an outlet for emotion, and also as a way of storing experiences and memories. This could be seen as a way of preserving the self or personhood, in those living with dementia, and as a way for a person to connect to their environment and to other people (Keady et al, 2020)

Key recommendations

This report presents a robust evaluation of the limited data available of the Greater moments Web App. It also offers a critical view of an evolving technology, which has been open to constant change, through its engagement with an advisory group, referred to as 'spotlight sessions' (See section 2.3) Recommendations are difficult to justify considering the amount of data which we have evaluated. However, we have been impressed by the potential which this Application has for individuals living with dementia, their care-partners and those who provide care and support in a professional capacity. As will be discussed throughout this report, the Web App under evaluation has lacked the flexibility of a downloadable app. This meant that comments were often added retrospectively, which could have created a problem for people with cognitive impairment. This lack of flexibility has no doubt also prevented a lot of impromptu comments/experiences, which may have been lost retrospectively, when other life influences take priority. Against this backdrop, we make the following recommendations towards the future development of the Greater Moments App:

1. Removal of Individual focus applied to DEMQUAL survey from the WebApp

Because the Greater Moments Web App has been used by people living with dementia, care-partners, professional carers and champions, it has been problematic to disaggregate data submitted only by those living with dementia from other users. Despite being given information relating to user ID's this did not result in valid data, since it was clear that some care-partners had attempted to fill this in for the person living with dementia, and therefore this data was excluded from the evaluation as it was deemed to be not subjective or obtained from the actual person. The evaluation would conclude that unless the DEMQUAL survey can be focused upon those living with dementia, it is felt that this should not be included on the Greater moments App going forward.

2. Professional carers to be given the opportunity to record their own subjective wellbeing, to support reflective practice, which would enhance care for people living with dementia.

Presently, the Web App entries made by professional carers, generally in care home environments, are related to resident's wellbeing. Whilst this is important, it appears to be a third person perspective of the resident and could be a repetition of care notes. This data has a place, and once developed as a native app, which is downloadable onto a smart phone or tablet, data could be recorded more easily in partnership with the resident and create rich experiential insights. However, either collected separately or alongside, we would see a huge potential in giving professional carers their own space to log their personal feelings/experiences of their role. Existing evidence which has looked at the benefits of keeping diarised accounts of experience in clinical practice, have mainly centred upon registered nurses, working in clinical environments (See: Munyewende and Rispel, 2014). This method of data collection, and environment would add unique knowledge to the body of literature and be of considerable interest to academic and clinical audiences.

3. Recruitment and mobilisation of Champions

At the time of writing there were 12 'champions', who were recruited to drive forward future engagement of the Greater moments App. The Champions were recruited informally via virtual engagement meetings with community partners. The Champions role at this time was to promote the app, support the Social Sense team with sourcing of local activities, events and services and to be consulted with throughout each step of the development. The Champions included people living with dementia, care partners and professionals working in the field of dementias and supporting care partners/carers. Without specific data relating to their role, and engagement, it was not possible to judge what their impact has had on engagement. However, interviews with dementia service professionals pointed to a need to recruit champions from clinical practice, with the intention of practitioners recommending the Greater Moments app early in the dementia journey, to gain maximum impact for the individual living with dementia and their care-partners.

4. For App developers to build into the downloadable (native) App a tool with which to determine social value/ return on investment.

We would recommend that a cost benefit model is devised for future commissioning. We are aware that Social Sense have on other projects been able to determine a social value and Social Return on Investment (SROI) rating and a similar achievement here could pave the way for more transformational type commissioning. The evaluators are happy to discuss the best way of quantifying benefits, impacts and demonstrating the value of the App.

Summary

This evaluation describes the ongoing development of the Greater Moments Web App. It documents how it is being used by people living with dementia, voluntary care partners, and those providing care and support on a professional basis. The App is constantly being updated and functionality refined making this evaluation a 'snap-shot' in its history. Such a technology which has the ability to support people with dementia and their care-partners along the care pathway and in different care settings is of interest to service providers and policy makers. Whilst it has the capacity to support memories and promote social interaction, it also has the potential to improve services, making them more dementia friendly, accessible and safer. As evaluators we also see that the evolving App could be used in care homes to support those providing care on a professional basis to diarise their experiences of working in often challenging environments. This could provide unique data and be a focus for further research.

1.0 Introduction

In the UK, around 850,000 people are currently living with dementia, with this figure predicted to rise to 1.6 million by 2040 (Alzheimer's Society, 2014) and around 540,000 people are acting as informal care-partners to someone with dementia (DoH, 2015). Over the last decade there has been a policy driven strategy to improve the quality of life and wellbeing for people living with dementia by improving societal awareness of dementia, and developing dementia care services (DoH, 2009; DoH, 2015). However, evidence suggests that people living with dementia can face discrimination (APPG, 2013), unacceptable variations in care quality (Alzheimer's Society, 2015) financial challenges accessing care (Alzheimer's Society, 2019) and encounter social barriers which prevent independence (APPG, 2019). The development of structured peer support, information networks, and the promotion of dementia friendly resources have been an identified goal of successive strategic policies (DoH, 2009; DoH, 2015; Duff, 2018) empowering people with dementia and their families to maintain social engagement and influence future service provision (DoH, 2012). A growing body of evidence has identified the inequalities for people living with dementia in accessing; information (Duff, 2018) post-diagnostic care and support (Wu et al, 2018) as well as experiencing fragmented services depending upon geographical location (Giebel et al, 2021).

The increase in the ageing population in the UK and the growing prevalence of dementia has created a societal challenge for policy makers to make it easier for those living with dementia to participate in civil society (Birks, 2016) and to 'live well' (Coffé and Bolzendahl, 2011). Underpinning the concept of dementia-friendly communities programme is the ethos of shared responsibility, to enable and empower people living with dementia to feel understood, valued and able to contribute to their community (Alzheimer's Society, 2021). Additionally, and importantly services need to raise awareness and challenge the stigma which often surrounds dementia (Buckner et al, 2019). In the UK, the Prime Minister's *Dementia Challenge* called for all businesses to become dementia-friendly by 2020 (Department of Health, 2015).

The overarching aim of the Web App has been to improve the wellbeing and quality of life for those living with dementia and their care-partners. Therefore, it seems pertinent to explore how wellbeing and quality of life are perceived and measured,

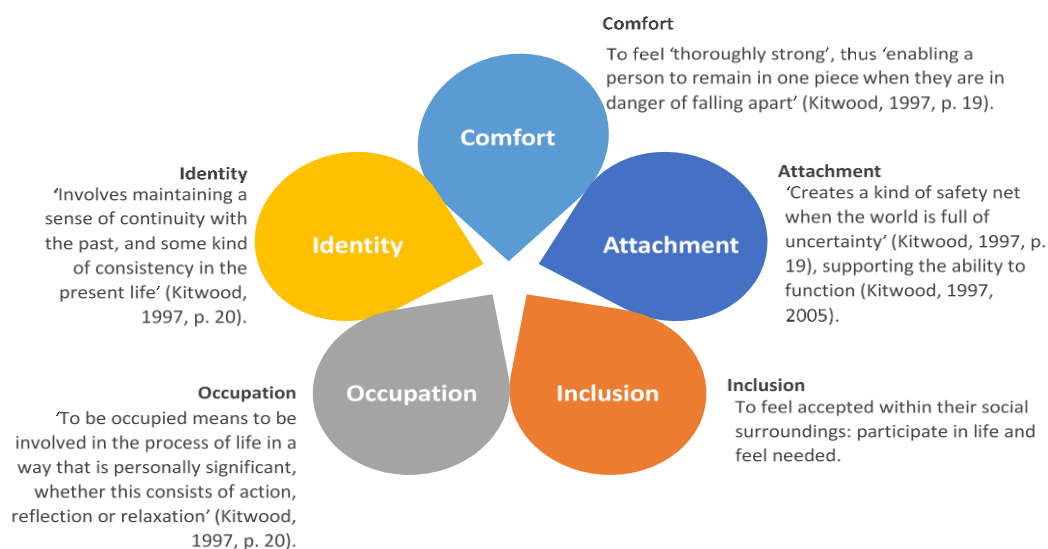
1.1 The concept of Wellbeing

The concept of wellbeing has attracted many definitions. It is described as a positive state of mind and body, of feeling safe, able to cope and having a sense of connection with people, communities and the wider environment (DoH 2010: p.12). Whilst Staricoff (2004) suggests that a person can be physically ill, yet still maintain a state of wellbeing since it is a state of acceptance of what is in the mind, body and spirit. The Department of Health (2014: p.6) state that: '*Wellbeing is about feeling good and functioning well and comprises an individual's experience of their life; and a comparison of life circumstances with social norms and values*'. Furthermore, the Department of Health (2014) description of wellbeing posits that it exists in two dimensions, with a subjective

or personal perspective, based on life satisfaction and an objective perspective, based on assumptions about fundamental human needs and rights. In contrast, Daykin et al (2016) identified wellbeing to have personal, cultural and social dimensions.

Taking a social-psychological stance, Kitwood conceived well-being and personhood differently from previous models which adopted a medical and behavioural focus (Kitwood, 1997). Kitwood stressed the importance of personhood and person-centred care, which he saw as fundamental to achieving well-being (Kitwood and Bredin, 1992). Kitwood (1997: p.19) defines personhood as ‘a standing or status that is bestowed upon one human being, by others, it implies recognition, respect and trust’. Using this definition of personhood Kitwood (1997) describes a person’s ‘well-being’ as being enhanced by the presence of recognition, respect and trust received from others, or in the absence of such behaviours, ‘illbeing’. Kitwood (1997:19) conceptualised that individuals living with dementia had five psychological needs: inclusion, attachment, comfort, identity, and occupation.

Image 1: An adapted diagram illustrating Kitwood’s (1997) 5 Psychological needs:



1.2 Quality of life

Quality of Life, and wellbeing are often used interchangeably, and treated as synonymous, although they are distinct concepts (Pinto et al, 2017). Considering that the Web App measures both wellbeing and quality of life, it is therefore pertinent to describe the latter. The World health Organisation definition of quality of life is:

‘An individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns’. (WHOQOL Group, 1995: p.1405).

Kwasky et al (2010) asserts that quality of life is affected in complex ways as factors such as mental and physical health, social relationships, environment and personal beliefs intersect. Quality of life is a growing area of interest in dementia research, although it remains a controversial topic (Söylemez et al, 2020) For people living with dementia, quality of life is generally considered to be a subjective, and multi-dimensional and dynamic construct, which includes the assessment and adaptation to the disease's impact on the whole person (Dichter, et al, 2016).

1.3 Measuring wellbeing and quality of life

The dynamic nature of any social interaction makes assessing the impact or improvement on wellbeing a complex task. The Web App asked users to input journal entries, and then rate their own wellbeing on a score from 1-9 where 1 is poor and 9 is the optimum. This gave a real time measurement of how users were feeling in that moment. The Web App also gave users the opportunity of answering a long form survey, consisting of 29 questions, with 5 alternative answers for each question. The long form survey asked users about their quality of life, and how they had been feeling, their social engagement, and any issues pertaining to memory problems they had experienced. The dementia quality of life survey (DEMQAL) is a standard validated tool, which was replicated in the Web App and purports to measure health related quality of life (HRQoL) which is a key outcome in dementia care and research (Bowling et al, 2015; Robertson et al, 2017). Optimising a person's quality of life, in the absence of a cure is the overarching goal of dementia care and support (Pickett et al, 2018)

2.0 The Greater Moments Web App

2.1 Study Brief

Manchester Metropolitan University were commissioned to undertake an evaluation of the 'Greater moments' digital platform, developed by Social Sense Ltd. The Web Application (Web App) principally sought to provide support to people living with dementia and their care-partners, by improving their quality of life and wellbeing. As a digital platform, it focused on individuals retained skills and their continued engagement in social situations. Indeed, from an overarching perspective, the Web App sought to influence facilities and events to make them more dementia friendly. Whilst the project initially looked to engage individuals and their care-partners early in their dementia journey, it also felt that it may benefit people in residential care, and those providing care on a professional basis. The evaluation therefore aimed to better understand the impact of connection on wellbeing and specifically how the app could make opportunities more visible and accessible for people.

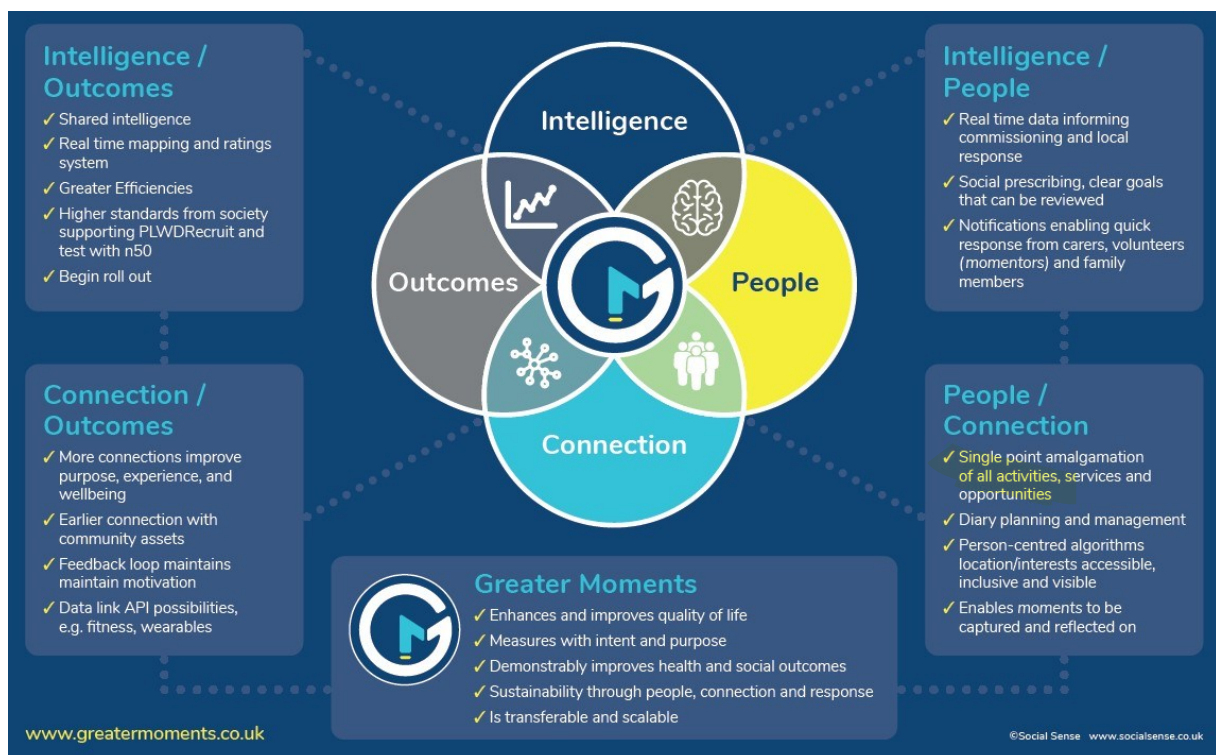
2.2 Development of the Greater moments App

Social Sense Ltd

Social Sense Limited was established in 2011 and has a 10-year history of changing lives at scale. From improving attitudes to health to reducing violent crime, they have engaged more than 200,000 children, young people, families and professionals across their programmes. The strategy for the company has been to consolidate and grow its own programmes alongside its growing consultancy arm which supports socially focussed businesses to establish themselves and scale (notably in the areas of Strategy, Consultation, Co-design, Social Marketing and Impact Measurement). The company have successfully licensed some of their products such as R U Different? www.rudifferent.co.uk and Change Up into various parts of the UK and Denmark and have an aspiration to now do the same with *Greater Moments* across the UK and Internationally. The company have co-founded 6 in house programmes and scaled most beyond their initially funded pilots. This evaluation relates to their 5th co-founded programme called Greater Moments, a mobile platform to support people with dementia and those around them.

Early ambitions for the App were:

- To build a barometer to better understand the lives of those living with Dementia in Greater Manchester
- Capture experiences affecting wellbeing, ranging from experiences in primary settings to interactions with local services
- Use intelligence to help support the wider aim of making Greater Manchester the best place in the UK to live with Dementia



Consultation.

In developing the Greater moments Web App social sense Ltd carried out an in-depth preparatory phase. This involved a period of consultation with potential users, who were people living with dementia, their care-partners, service providers, commissioners and policy makers. The purpose of this was to understand people's needs, context and practices, and how the potential product could be designed to address these requirements. This consultation phase became the first stage in the co-design process.

Scoping exercise

The team conducted a systematic literature search exploring dementia care and wellbeing. This led to a specific interest in the work of Professor Keady, whose research looked at the concept of 'moments' and how people living with dementia could experience and record moments in their everyday life, and also how people can connect to the self, their environment and other people. A scoping exercise also took place around what Apps already existed on the market, so to avoid any duplication. Combining these findings, the team at Social Sense were able to identify gaps in both the literature and the market, and map these against strategic drivers in Health and Social Care policy. The following infographic shows how the Web App was developed to meet the needs of the individual, their care-partners, service providers, and the local community.

Problems in aging sector, health and social care

Carers & People Living with Dementia		Local Community		Health & Social Care System	
					
Lack of connection purpose, dips in wellbeing	Support often not accessible, inclusive or tailored	Poor visibility and connectivity of activities and services	Inconsistent approaches and quality standards	Significant social data gaps	High system costs and dependencies in social care

Solutions addressed by Greater Moments

Opportunity to enjoy new activity and connection	Greater Moments delivers a person-centred experience	Single point access to services, activities and events	Ratings system identifies gaps and drives up quality standards	Real time data gathering on 'moments' not just services	Societal benefit for people living independently for longer
					

Funding

The pilot project to develop a Web App for people living with dementia, which had the capacity to monitor and improve wellbeing and quality of life, received funding from

'Dementia United' which is a Greater Manchester programme for dementia. Dementia United has the overarching aim of making the Greater Manchester region the best place to live for people with dementia and their care-partners. The programme's goals are articulated as providing access to dementia care services for all, increasing independence for those living with dementia and ensuring high standards of dementia care across the region. The Dementia Carers Expert Reference Group (DCERG) have been consulted and engaged with throughout the process from the initial inception of the ideas to having regular updates at their forum meetings.

2.3 Co-design: Spotlight sessions

The team at Social Sense organised 4 online meetings, which invited people with an interest in the Greater Moments Web App to become involved in a discussion forum. Attendees came from a broad range of disciplines, including people living with dementia, care-partners and former care-partners, app users, professionals working within the field of dementia, commissioners, third sector representatives and people from business and enterprise. The purpose of each session was for participants to engage with the App developers, on key features of the App, informing the next phases of technical development. This process allowed for co-design to take place, which is a vital part of this evolving technology.

2.4 Improving service provision

The Greater Moments Web Application reflects the person-centred approach by Kitwood (1997) which posits that individuals can live positively with dementia, focusing on their retained skills, as oppose to centring on a deficit perspective. Evidence suggests that people living with dementia and their care-partners encounter difficulties in accessing services and events which are not dementia friendly, and this has adverse effects on their feelings of social inclusion (Greenwood et al, 2013) Indeed, access to post diagnostic support is strongly associated to improved wellbeing (Alzheimer's Disease International, 2016) and provides important social engagement (Kelly and Innes, 2014) reducing anxiety and social isolation (Szymczynska et al, 2010). The main aim of supportive services, following diagnosis is to help those living with dementia and their care-partners to continue to live well, provide information, and where possible to delay admission to long term care (O'Shea et al, 2018).

Post diagnostic support is a vital component of contemporary and future decision making for those living with dementia and their care-partners, and as such underpins UK dementia policy and strategy (DoH, 2016; NICE, 2018). However, despite this ongoing policy focus, aimed at improving dementia services in the UK, evidence shows that there is a fragmented system of statutory and third sector service provision (Wheatley et al, 2018). Often, the main barrier for people newly diagnosed with dementia is the lack of signposting to services, causing individuals to struggle to navigate the complex health and social care arena, which is often unconnected to informal and third sector groups.

The Greater moments Web Application has the potential to bridge a long-held data gap between social and clinical, commissioners, support services and project champions who can respond earlier, more efficiently and intelligently – leading to genuine, realisable return on investment within the social care system. To date (reported on 19/07/21) the company have 147 Web App users, which include 28 people who are living with dementia, 59 care-partners and 60 people who are paid care workers. The Web App identified 170 services/organisations across the GM region, ranging from dementia specific organisations such as ‘The Lewy Body Society’ to organisations providing services to the general public such as the ‘National football Museum’. Taking a similar vein, the 286 activities and events which have been advertised on the Web App have been both dementia specific, such as an online event focusing on ‘caring for someone with dementia, to face-face events of general interest such as ‘Bolton food and drink festival’ or ‘The River city cruise’.

2.5 Journal entries: Recording a moment

An important feature of the Web App is that it allows individuals to input a journal entry, described by the Web App as a moment. When users add a journal entry, they are also prompted to add a wellbeing score, which provides an indication of their subjective feelings at that moment. This journal entry acts as a contemporaneous record of an individual’s experiences, views, thoughts, and feelings. As data collection tools, diaries can be used to gather in-depth information about an individual’s experience, behaviours and personal thoughts (Alaszewski, 2007). Diarised accounts can enrich our understanding of living with dementia by affording a highly personal vantage-point, embedded within a specific context. Giving individuals the opportunity to document their first-hand experiences, can according to Travers (2011) be a cathartic experience, helping to overcome the discomfort of articulating their feelings in an interview setting, which can be advantageous when tackling sensitive issues.

The concept of recording a moment is set against the notion that an individual can continue to experience ‘greater moments’ following the onset of dementia. Helping to create and record a moment draws on the work of Keady et al (2020) who contended that for people living with dementia a moment can be captured in real-time, and whilst transitory in nature can be recorded to help preserve a person’s identity and personhood. Professor Keady’s work recognised that ‘being in the moment’ can be used as a way of connecting an individual who is living with dementia to their sense of self, their environment, and the people around them. Similarly, ‘being in the moment’ allows those caring for someone with dementia to ‘be with them’ and try to understand the way in which they are experiencing everyday life (Keady et al, 2020). This was well illustrated in a study by Dowlen et al (2021) which used ‘in the moment’ as a term of reference to show how an improvised musical performance could facilitate a group of people to connect ‘in the moment’ to share an experience. Certainly, by re-thinking and re-positioning the experiences of individuals living with dementia through the conceptualisation of being ‘in the moment’ this intersects with a person-centred approach, which is both reflexive and intuitive (Keady et al, 2020). The critical message conveyed through Keady’s, and colleagues work is the need for people living with

dementia to remain central in the co-design and participatory nature of research, continually exploring moments of connection and disconnection. Indeed, Bryden (2005) writing from the viewpoint of someone herself living with dementia wrote ‘many of us seek earnestly for this sense of the present time, the sense of ‘now’ of how to live each moment and treasure it as if it were the only experience to look at and wonder at’ (p.11) recording these moments so that they were not ‘lost forever’ (p.101). In considering ‘moments’ as fluid concepts, moments can be recorded and linked together to provide a deeper understanding of the lived experience of dementia, through the perspectives of those living with a diagnosis, care-partners, and professionals in the field of dementia.

3.0 Study design

This evaluation delivers a robust analysis of secondary data which was collected by the Social sense team. An ethical approach to data collection was followed throughout the study, with all participants consenting to their data being used as part of the evaluation. It was noted that the staff at *Social Sense* who were involved in data collection followed good practice guidelines for research.

The study aimed to assess the efficacy, validity and usefulness of the data being collected, to determine its value, and to identify any gaps or limitations. The Web App was designed to improve people’s lives who were living with dementia, connecting them to services and support, allowing them to record ‘moments’ in their day, and influence service provision. From a broader perspective, the Web App allows organisations, Professional in the field of dementias, commissioners, and paid carers to have an overarching view of service provision, respond to feedback and promote a dementia-friendly approach.

3.1 Data collection

Data has been collected through the Web App from 26th October 2020 until 3rd August 2021. Data was anonymised prior to secondary analysis. Quantitative data collected was: User inputted wellbeing scores; assisted DEMQOL surveys; short form surveys; Service/event ratings and analytical data on usage, traffic and reviews. Qualitative data was in the form of: Free text data capture from: user inputted ‘moments’ data and ‘happenings’ data, and interview transcripts from three semi-structured interviews with professionals working within the dementia sector exploring their role and the impact which they observe on users.

The team at Social Sense acknowledged the lack of data from all sources provided to the evaluators, which appears to be due to the problems created by the COVID-19 pandemic (See section on contextual barriers). The development of the Web App however is a constantly evolving process, which also involves an ‘advisory team’ (Spotlight sessions) which has convened on four occasions to help co-design the

forthcoming version, which will see it change from a web-based app to a native app which is multi-tenanted

3.1.1 Evaluated data

The data supplied for the evaluation is described below, and was received by the evaluators on 2nd August, with all follow up data received by 11th August. This has meant that the evaluators have had a limited time to work on the analysis, which was required to be completed before 1st September 2021. The evaluators acknowledge the kind co-operation and accessibility of the Social Sense team; Gary Lovatt, Stacey Adams and Charlotte Yiatrou.

Data Source 1: Logged entry of 'Happenings' data

Excel formatted data showed 79 'happenings' which were recorded, by 23 users over the evaluated time period (26/10/20-3/08/21). Participants were able to select one choice from a list of eight pre-arranged activities (List: Went out; Attended an appointment; Did an activity; Spoke to family/friends; Visit; Sports event; Health problem; Unwell). Participants scored their wellbeing using a Likert scale from 1-9 (Where 1 is poor, and 9 is Very high). Participants could also use a free text box to add further information.

Data Source 2: logged entry of 'Moments' on Wellbeing sample data

Excel formatted data showed 101 wellbeing scores were logged by 40 users (26/10/20-3/08/21). Participants were able to record a 'moment', which could be an experience, or feeling, using free text and they were then prompted to record a wellbeing score. Not all participants used the free text feature, with some just recording a wellbeing score.

Data Source 3: Short Form Survey

A user survey was carried out in May 2021 whereby all registered users were asked to complete a short survey asking their experiences and usefulness of the Web App. Ten users took part, three were people living with dementia, six were carers and one declined to answer. Only 2 users completed all questions.

Data Source 4: DEMQUAL survey

A 29 question DEMQUAL survey was available for any users to complete at any time during the evaluated time period (26/10/20- 3/08/21) 21 participants completed the survey on 30 occasions.

Data Source 5: Qualitative interviews

All 'Greater moments' Web App users were invited to take part in a qualitative interview to share their experiences and thoughts of using the Web App. Three semi-structured interviews were conducted by Stacey Adams and Charlotte Yiatrou (CY) with professionals working in the field of dementia. A topic guide (See Appendix 2) was created for use within all interviews to enhance data collection.

Data Source 6: Service sample data

Excel formatted data showed that 5 users had rated 17 different services/organisations with a score from 1-10 (Where 1 is poor and 10 is excellent)

Data Source 7: List of events and organisations

Excel formatted data showed that 170 organisations were identified, and 286 events were advertised across the Greater Moments Web App. The Social Sense Team link regularly with Champions and partners across Greater Manchester to identify services, activities and events to be added to the app, this is very much a live and ongoing process. The App allowed users to see details of organisations, and events, occurring across the evaluated time period, allowing either on-line or face-to face access. Data was supplied for information only, so the evaluators could gain a better understanding of the day-to-day use and reach of the Web App.

Data Source 8: User traffic across Greater Moments/ Social sense media profile.

Data was supplied showing the numbers of people engaging through social media, and other promotional campaigns which have been run by the Greater Moments team. Results show the following levels of activity: Instagram: 303 Followers; Twitter: 1,083 Followers; Facebook: 287 Likes; YouTube: 13 Subscribers; LinkedIn: 440 followers.

3.2 Contextual barriers impacting data collection

The roll-out of the Web App, and subsequent data collection and evaluation took place during the COVID- 19 pandemic, which impacted the development of the Greater moments Web App in the following ways:

- **Promotion:** Promoting the Web App to people living with dementia and their care-partners, service providers, events/organisations were confined to online delivery, possibly excluding those without computer access. There was also no opportunity for face-to-face contact with individuals who needed support to navigate the app.
- **Recruitment:** Recruitment is interconnected with promotion, as there was no face-to-face contact permitted, which prevented the company making presentations to user groups, care home staff, and healthcare professionals. Lack of face-to-face contact may also have impacted this evaluation, as the company had difficulty in recruiting individuals to take part in qualitative interviews.
- **Visiting events:** Individuals living with dementia, in the community and in care homes were advised to 'shield' and self-isolate during the pandemic, leaving home only for essential activities. This meant that they did not visit any events or activities which were promoted on the Web App.
- **Competing priorities of users:** It was evident through qualitative interviews with Professional in the field of dementias and champions, that they had to prioritise immediate health and safety concerns ahead of activity co-ordination.

- **Closure of non-essential services:** Events and activities were closed throughout the period from March 2020 to approximately July 2021 in line with Government directives to non-essential services. This meant that a key function of the Web App, in reviewing events, venues and activities could not be actioned.
- **Funding provision.** It is of significance to note that there were gaps in funding provision which had a significant impact upon the activity and development of the app as well as an impact upon engagement. With the second year of funding ending in March 2021 the Social Sense team began to wind down activity, recruitment of users and engagement with community partners from January 2021. Focusing on business development for sustainability at a time when no further funding was available. However, they were granted a six-month extension from April 2021. The break in comms across the board meant that it became more challenging to re-engage partners and communities with the app and once again with the funding being temporary people are notably reluctant to offer support and resource to a project that may be winding down shortly after.

3.3 Engagement strategies undertaken

This evaluation acknowledges the impacts, detailed above, which the COVID-19 pandemic has had on the recruitment and engagement of Web App users. Despite this inability to present at events and to clinical practitioners, working in the field of dementia, the team responsible for the Greater moments App have launched two successful initiatives. The first was the hosting of a virtual Christmas party, which was streamed live, and on demand to care homes, and community dwelling people living with dementia and their care-partners. The second, more recent initiative was the butterfly garden kit, which was given to participating care homes. The details of both initiatives can be found below.

Greater Moments Christmas event (20/12/21)

Image 2: Web advertisement of virtual event



The Greater Moments Christmas Event was shown to people living with dementia, care-partners, and care homes, to create an accessible festive show. The event was promoted across the Greater moments Web App and Facebook sites, and screened live via You Tube to 100 people, and a further 720 people using 'on-demand' streaming.

The show also received a great deal of local publicity, including [this](#) article from Prolific North. In an attempt to capture the anecdotal feedback from the event, participants were asked to retrospectively comment on their subjective wellbeing before and after the Christmas Event in order for the Greater Moments team to see the impact the event has had on App user's wellbeing.

Image 3 Short evaluation survey re Christmas party

Q2. If you remember back to BEFORE the Greater Moments Christmas event. What would you rate your mood on a scale of 1-10?(When 1 is "feeling low" and 10 is "very happy")					
Answer Choices	Average	Min	Max	Std. Deviation	Response Total
1	7.55	5.00	9.00	1.44	11
Answered: 11 Skipped: 0					Response Total: 11

Q3. If you remember back to AFTER the Greater Moments Christmas event. What would you rate your wellbeing on a scale of 1-10?(When 1 is "feeling low" and 10 is "very happy")					
Answer Choices	Average	Min	Max	Std. Deviation	Response Total
1	8.27	7.00	10.00	0.96	11
Answered: 11 Skipped: 0					Response Total: 11

Looking at the responses taken from 11 different people, results show the positive impact the Greater Moments Event has had on individual's wellbeing.

The Greater Moments Facebook site also recorded that 13,936 people reached the site, with 1,320 post engagement recorded between December 7th and January 3rd, 2021

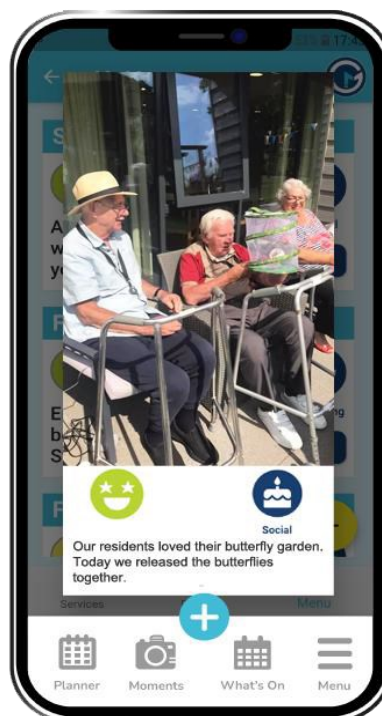
Greater moments butterfly garden kit

The butterfly garden project was launched to engage care homes with the app, by providing free butterfly garden kits for care homes where they support people living with dementia. In return, the care homes registered for the app and, signed up a minimum of three of their residents and, were asked to record their wellbeing and use the moments journal.

Image 4: Promotional initiative of butterfly garden



As can be seen in the qualitative data, residents and professional carers in the care homes have enjoyed this new form of interaction, which has also resulted in creating conversations with staff and family members.



Live Twitter Chats

In a bid to maintain engagement with the greater Moments Twitter followers, the team got involved with 'Diverse Alzheimer's' to discuss self-care and wellbeing. The initiative generated a positive reaction to the Greater Moments Web App, receiving 10 likes and 5 retweets. During the discussion the team were live on Twitter across four devices (two laptops and two mobile phones) for 2.5 hours answering questions and responding to queries regarding the app, facilitating a lively debate and generating interest in Greater Moments.

Collaboration with Gold Key Media

Lifestyle Magazine

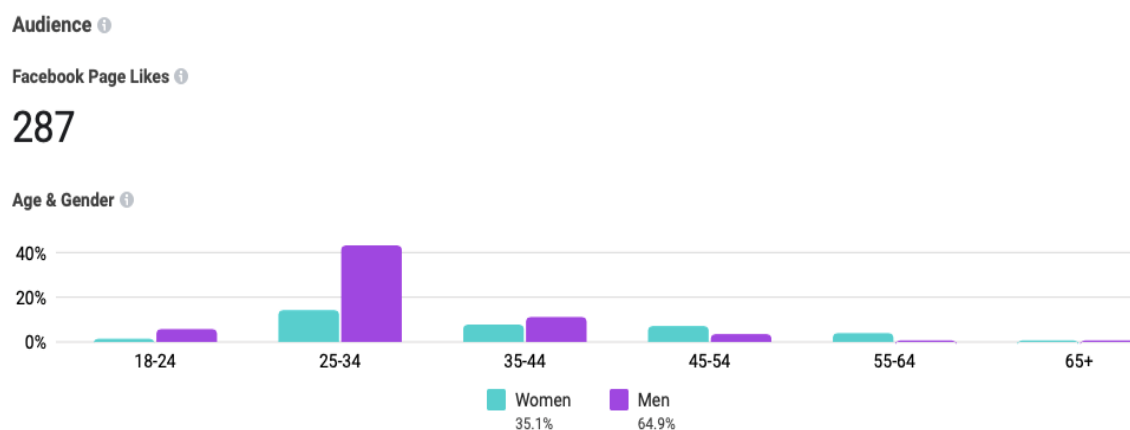
Greater Moments partnered with Gold Key Media in the months of November 2020 – January 2021 to offer Greater Manchester care home residents hundreds of complimentary lifestyle magazines. The promotion is estimated to have reached a further 52 people, generating 3 online reactions. Link can be accessed below:

<https://www.greatermoments.org.uk/free-magazines-bring-greater-moments-to-care-residents/>

Social media

The Gold Key Media collaboration with Greater Moments social media post failed to reach a wide audience when promoted on Facebook, when looking into reasons as to why this could be, the top age demographic for the Facebook page likes is 25-34 which is not Greater Moments target audience age when targeting care home residents. (<https://www.facebook.com/socialsenseuk>)

Image 5 Facebook data bar chart



Additionally, Social Sense partnered with Salford CVS who created and delivered goodie bags to 27 care homes in Salford which included a selection of the magazines.

Collaboration with Bright Copper Kettles CIC

Activity packs

During the spring months of 2021 Greater Moments and Bright Copper Kettles CIC joined together in collaboration to offer free Greater Moments app users the opportunity to receive free activity packs. To promote this initiative, both Bright Copper Kettles CIC and Greater Moments shared the following blogs on their websites to drive engagement. There was also some PR coverage within the local media [Greater Manchester Dementia app offers digital activities during winter months Prolific North](#)

Alongside this, it was shared on social media, with local services and charities being tagged. A positive response was received, with 159 views of the post, and a spike in the number of video views (79 views for the Web App walk through 1 and 28 views of the Web App walk through 2)

Dementia action Week

The Greater moments Web App promoted a positive message throughout dementia action week, with 2 users recording a video to share the message: 'that there are #GreaterMomentsAhead after a diagnosis of dementia'. Findings suggest that the videos had an estimated reach of 563, with post engagement of 22 people. Another message was disseminated by providing a screenshot of 2 users, holding a handwritten note that spreads the Greater Moments message of "There is life after a diagnosis" The results show that the screenshot reached 386 people and generated 48 reactions, this including Likes, Shares and Comments.

4.0 Data analysis

Qualitative data was analysed using Braun and Clarke's (2006) six phase approach to thematic analysis. See table below.

Table 1 Braun and Clarke's (2006) six-phase approach to thematic analysis

Braun and Clarke's (2006) six-phase approach to thematic analysis	
Stage 1: Familiarisation with the data	Team at Social Sense, Stacey Adams (SA) and Charlotte Yiatrou (CY) conducted the semi-structured interviews and the evaluators transcribed verbatim. Transcriptions were read repeatedly to enable researchers to be immersed in the data Web App data with free text was anonymised by SA and CY and sent via email to LC and AA
Stage 2: Initial coding of the data	The evaluator LC coded the data by hand

Stage 3: Data searched for themes	Data was searched for initial themes and discussed Findings reviewed for coherence and credibility by evaluators LC and AA
Stage 4: Themes reviewed and refined	Themes were repeatedly reviewed and refined into significant themes
Stage 5: Themes defined and named	Following a consensus of opinion. Final themes were defined
Stage 6: Evaluation report produced	LC produced an initial draft of the report, which was reviewed by AA. The team at Social Sense were consulted over terminology used in the report and supplied information as requested.

4.1 Research questions

Data analysis sought to inform the following research questions:

1. Is the Greater Moments Web App delivering a worthwhile service to people living with dementia, and does it have a positive impact on individuals wellbeing and Quality of Life?
2. Is the Greater Moments Web App increasing awareness of services for people living with dementia within their local area?
3. Is the Greater Moments Web App making services in Greater Manchester more accessible and accommodating for people living with dementia, through feedback?
4. What is the impact of Champions upon the Greater Moments Web App?
5. What is the social value (ROI) of the Greater moments Web App?

5.0 Results

5.1 Qualitative data

All users of the Web App had first-hand experience of Dementia, as unpaid care partners, Professional in the field of dementias, champions or those currently living with dementia. The journal entries reflected their individual thoughts, feelings, coping mechanisms and experiences they had encountered in finding ways to live positively with dementia and to overcome the unique challenges which dementia created.

Findings reveal the cathartic nature of the recording of 'greater moments', where people living with dementia, and their care-partners document their feelings, experiences, and challenges. The Web App was also made available to professional carers who used it to record their perceptions of someone who was living with dementia. The primary and subordinate themes are summarised in table below.

Table 2 themes arising from qualitative data

Table 2. Themes
Theme 1: Experiences during the COVID-19 pandemic:
Theme 2: The role of the care-partner
Subordinate theme 2a: Care-partner stress
Subordinate theme 2b: Care-partner fear
Subordinate theme 2c: Care-partner challenges
Theme 3: Connectivity
Theme 4: Promoting wellbeing
Subordinate theme 4a: Importance of social interaction
Subordinate theme 4b feeling settled
Theme 5: Competing Priorities
Theme 6: Meeting the needs of users
Theme 7: The Greater Moments App development

5.2 Contextual themes

Theme 1: Experiences during the COVID-19 pandemic

In March 2020, the UK Government announced 'lock-down' guidelines, advising older people, and those at increased risk to shield themselves from the virus (Gov.uk, 2020). Evidence suggests that those living with dementia were disproportionately affected by the pandemic due to increased risk of infection and mortality (Atkins et al, 2020). As people were forced to self-isolate, face to face support groups closed and visits to care homes prohibited, people living with dementia were affected by the consequential social isolation and reduced access to health and social care (Dementia UK, 2020). The qualitative data presented in this section is from the *Wellbeing sample survey* and the *Happening sample survey*. Quantitative data from these two data sets appears after the qualitative data.

Findings show that people living with dementia and their care-partners who resided in a community setting, experienced frustration and isolation from not being able to see family and friends. Users rated their wellbeing as 1/10 on occasions. In one entry log we

note that a person who is living with dementia visualizes their feeling with a sad face symbol, and scored their wellbeing at 1/10, commenting:

PLWD 283: Anxiety from self-isolating

Feeling isolated from family and friends was a major concern to many throughout the pandemic. The following text shows the lack of personal contact with family was distressing.

Voluntary Care-partner 202: Saw [name] and girls through the window, think that was worse than not seeing them at all

Again, the person's wellbeing score was adversely affected, and reduced to 1/10. Interestingly, the person observes that they would have preferred not seeing them at all, rather than to see them under the circumstances where they were allowed no physical contact.

In another journal entry, a care-partner makes the observation that technology is malfunctioning, which whilst in pre-covid conditions, this may have been an irritation, during the pandemic this means that they are isolated from others. The play on words of 'not functioning today' may infer that they, as a person were not functioning very well at that time, as they also make mention of the negative impact of lockdown and scores her wellbeing at a low 3/10.

Voluntary Care-partner 202: feel like every tab on a pc is open and frozen - not functioning today. Lockdown has got to me today well and truly (WS 3/10)

For paid carers and professionals working in the field of dementia, the pandemic has meant that there is a huge emphasis on safety, to keep people safe, which had to take a greater priority than providing creative or stimulating interventions. In the following entry, the professional carer writes about her concerns, and the dilemmas facing her.

Professional Carer 186: I've been asked by my client's family to take my client's out tomorrow to the garden centre. I'm looking forward to it as are my clients. I'm just a little concerned that it might be very busy as it's two days before the national lockdown rules apply to non-essential shops. So, I'm thinking ahead of the visit ways to keep my clients covid safe whilst out on tomorrows visit.

In another account a person living with dementia asks a series of hypothetical questions in their log, as they try to make sense of the imposed rules around lockdown.

PLWD 201: why can't I go out? Why can't I drive? I want to go to groups.

This style of entry clearly demonstrates that there is a cathartic component to diarising their thoughts, acting as a release mechanism for frustration. The person's distress was also seen in their wellbeing score, which was 3/10. We can observe the importance attached to engaging in social activities, and support groups, for the person living with dementia and the anxiety which is apparent because of their social isolation.

volunteers and support bubble?

Theme 2: The role of the care-partner

Subordinate theme 2a: Care-partner stress

Users who were care-partners expressed their anxiety and frustration at dealing with the symptoms of dementia. For many it was the constant repetition of behaviour or the persons differing perceptions, which were reflecting reality. The following excerpt of text, is one for which the subject is recorded a few times by the same person, showing how the person with dementia believes that it is Christmas every day. The care-partner shares how this behaviour presents as an ongoing problem, particularly as the person with dementia keeps getting agitated that arrangements for Christmas have not yet been completed.

Voluntary Care-partner 202: 'Thinks it's Christmas every day'

which is then followed up a few days later when they add

Voluntary Care-partner 202: 'Mithering about car, and Christmas. Worried about his mobility'

The care partner articulates the confusion which the person living with dementia feels around date and time where they think it is Christmas every day. Linguistically we see the first entry taking a matter-of-fact approach, letting us assume that this behaviour has been dealt with in the past, and has become a common problem to negotiate. This assumption is also played out in their wellbeing score which has only reduced slightly to 7/10. However, in the second log entry, the word choice reflects more frustration, with the term, 'mithering' used to convey that the person with dementia is perhaps anxious, and repetitive in their behaviour. This heightened state of emotion is also mirrored in the care-partners wellbeing score of 3/10, illustrating the distress being experienced. In the

next entry, we are given a glimpse of the care-burden being experienced at that moment in time:

Voluntary Care-partner 202: *worn out and sad. [PLWD] being very verbally aggressive (WBS 1/10)*

The care-partner's openness with the Web App articulates the struggle of dealing with the sometimes-challenging behaviour they are encountering. However, we can assume that the App is allowing them a safe space to articulate their feelings, and that the frequent diarised accounts are helping the care-partner to cope with the situation.

Subordinate theme 2b: Care-partner fear

One user, who was a care-partner made three different logs which centre on the all-consuming nature of caregiving. Many of the logged text mention the tiredness they are feeling. In the following two accounts they mention the fear around forgetting vital parts of the caring process, focussing on the medication.

Voluntary Care-partner 202: *too much to remember, frightened of forgetting anything like ordering medication (WS 3/10)*

Voluntary Care-partner 202: *Remembering to order meds and sort appointments out. Must make sure they have everything they need.*

The next piece of text gives a poignant reminder of how devastating dementia can be for family and friends, and the fear that their father, who has dementia, will soon not have any memories of them.

Voluntary Care-partner 202: *"How much longer will Dad remember me?"*

The same person then writes about a family crisis, summing up how hard she is finding it, to cope with family responsibilities, and trying to find ways of coping.

Voluntary Care-partner 202: *After a lovely afternoon yesterday [name of person] was taken into hospital with an angina attack after just coming home from being admitted a week. Be constantly watching [name of person] and Mum and Dad - how much more can I take.*

The text is a reminder of the fragility of life, and how the person's day suddenly changed so rapidly, with the final words questioning her own ability to cope.

Subordinate theme 2c: Care-partner challenges

As dementia progresses, many people develop behaviours that can be challenging and can include aggression and restlessness. These symptoms can be difficult to cope with for care-partners and those around them. However, in the next text, we hear how the person living with dementia is feeling and glimpse their insight into the disease.

PLWD 201: verbally aggressive, feel everyone is out to get me

In the above entry, the individual scores their wellbeing at 1/10, demonstrating the desperation, which is being felt, which is mirrored in the text, feeling that everyone is against them. This text could also illustrate the fear that they are feeling, at their own and other people's behaviour. The next excerpts offer descriptions of some of the challenges facing professional carers who are working in a care home environment, where one person's behaviour can have negative impacts on other residents:

Professional carer 477: *[PLWD] is very anxious today and has been pacing around the home. (WS*

Professional carer 478: *[PLWD] remains unsettled today, she has been very distressed and restless. (WS 5)*

Professional carer 826: *[PLWD] has been verbally aggressive towards over residents today. She is suffering from paranoia and periods of unsettled behaviour.*

The text observes the challenging nature of care provision, and the invaluable role which is being undertaken by the professional carers. The text also shows how well the care staff know the residents, as they articulate the behaviour that they are watching, and allows some insight into the distress which the residents are feeling.

Theme 3: Connectivity

The greater moments Web App was used by some as a journal to enable users to enter their experiences, thoughts and feelings, as well as being a resource which could help people to know what events, venues and support agencies are available to them in the local area. A theme of connectivity was present across many of the entries, as the following texts demonstrate. Whilst social engagement is a central part of wellbeing, it has become ever more important throughout the pandemic. *The journal entries which*

mention social contact with friends and family, show that this is linked with higher wellbeing scores. The first logged entries refer to online connectivity:

PLWD 201: Saw friends on a zoom (WBS of 7/10)

PLWD 201: In a much better mood today. Facetimed great grandchildren (WBS 5/10)

PLWD 241: I've chatted with my grandkids (WBS of 7/10)

Seeing family and friends in person, after a long period with no physical contact was clearly an important aspect for people's wellbeing, with the following text referring to physical contact which took place:

Professional carer 480 [PLWD] is very bright and has enjoyed a visit from her eldest daughter. (WBS 9/10)

Professional carer 479 [PLWD] has enjoyed a visit from her niece and has enjoyed watching the butterflies grow. (WBS 7/10)

PLWD 490: had a visit from my husband (WBS 7/10)

Voluntary Care-partner 202: had a lovely time with [family members names] and facetimed family (WBS 7/10)

In the following account, the professional carer describes the positive impact on wellbeing which was observed as a resident living with dementia receives a visit from a family member. She narrates how the resident had been anxious, before the visit, and then later perceives their wellbeing to be 7/10

Professional carer 477: [PLWD] is very anxious today and has been pacing around the home. However [PLWD] enjoyed a visit from her son [Name] (WBS 7/10)

However, the data also reported episodes of distress which was associated with contact. The following comments were logged by a professional carer, observing a resident's behaviour and perceived wellbeing score, where visits from family are causing agitation.

Professional carer 478: [PLWD] is very unsettled and distressed at present. [She] had a visit from her son but this caused her a great amount of distress. (WBS 3/10)

Professional carer 478: *[PLWD] is very unsettled today, she has been restless and shouting out. [She] spoke with her son on the telephone. (WBS 5/10)*

Connectivity was clearly a key area of importance during the pandemic, particularly for people living with dementia, care-partners, and paid care providers. The loss of face-to-face support prohibited visiting, and self-isolation have had profound impacts on individuals. The next theme draws on the factors which can impact wellbeing

Theme 4: Promoting wellbeing

Subordinate theme 4a: Importance of social interaction

The *Greater Moments* Web App is underpinned by the belief that people with dementia can live positively and continue to enjoy life following diagnosis. In the following text we see that one of the users, who lives with dementia has recorded high wellbeing scores, for engagement activities, such as playing boccia, dominoes and watching old films with friends. These relatively simple events have created a stimulus for both the person with dementia and their care-partner and both recorded positive experiences, and increased wellbeing scores, an example being:

PLWD 201: Had a lovely time watching old movies with [friend] , then a few games of dominoes.

In a passage of text, referencing a separate occasion, a care-partner shares their thoughts on why they have had a good afternoon.

Voluntary Care-partner 202: Had a lovely lunch and watched a movie with mum and dad this afternoon (WS 5/10)

An event which was discussed by many of the users who were either professional carers or residents in a care home was the arrival of a butterfly garden, which had been gifted to a number of care homes by the SocialSense team (See earlier description). The kit contained caterpillars, which the residents and professional carers all showed great interest in. The butterfly kit created a topic for conversation, as App users mentioned receiving, opening and examining the set:

Professional carer 488: *[PLWD] enjoyed helping to open the butterfly kit*

Professional carer 489: *Had a lovely visit from my wife and told her about the butterflies*

Professional carer 489: *[PLWD] liked the butterfly kit*

Professional carer 490: *[PLWD] liked looking at the caterpillars and how they moved*

PLWD 241: *the butterfly kit was great*

PLWD 241: *excited waiting for the butterflies to emerge*

The butterfly kit appears to have been a very significant engagement tool, and allowed all those involved the taste of a new activity, sparking interest and engagement.

Subordinate theme 4b feeling settled and content

The observation and the perception of being 'settled' was something which was repeatedly logged by professional carers, when describing the wellbeing of residents. To be 'settled' implies contentment, and an absence of agitation, which for many professional carers working in care homes will be times when the feeling of being settled is reciprocated in their own wellbeing. The following text show some of the entries which were logged.

Professional carer 476: *[PLWD] is settled today and watching the Olympics (WBS 7/10)*

Professional carer 477: *[PLWD] is very settled today and has enjoyed the afternoon entertainment (WBS 7/10)*

Professional carer 837: *[PLWD] has been very bright and engaging. She responded very well to the entertainment and has been singing this afternoon. (WS 7/10)*

Professional carer 838: *[PLWD] is bright today, she received a new book and some chocolates in the post from her daughter. (WBS 7/10)*

The next entries are from people living with dementia, observing their own mood, and wellbeing score. Whilst perhaps the details are sparse for evaluation purposes, it does show that individuals with dementia are engaging with the Web App and recording 'moments', often retrospectively.

PLWD 488: *enjoyed afternoon tea yesterday (5/10)*

PLWD 488: *I'm feeling better now the weather has cooled down (7/10)*

PLWD 206: How lovely my walk was this past weekend (WBS 7/10)

The following journal entry shows the interconnection between the person living with dementia and their care-partner, where the care-partners articulates how their feelings mirror the person with dementia.

Voluntary Care-partner 202: Dad happy I am happy

The Web App has allowed individuals to share their everyday feelings, experiences and insights into how their own and others wellbeing is influenced by the environment, other people and their own emotions.

Theme 5 Competing priorities

Interview data was obtained from three professionals working in the field of dementia who spoke about their experiences throughout the pandemic. The professional in the field of dementia number 1 worked as an activities co-ordinator within the care home sector and spoke about the competing priorities she has experienced, in which she had to take on new roles around health and safety, which meant that activities with clients had to be shortened. This is perhaps best summed up in her own words:

It felt like we were paddling against the tide... There was no extra help. The focus was on keeping people safe. Nothing else mattered. [Professional in the field of dementia 1]

The imagery of 'paddling against the tide' allows the visualisation of how hard it must have been for professional staff working in care homes, trying to survive amidst the threat of the pandemic. Indeed, during the interview she tells of deaths from Covid in nearby care homes, and the very real dangers which were faced on a daily basis. Professional in the field of dementia number 1 had limited experience of using the Web App, mainly due to the fact that she required training on it, but until now, when restrictions were beginning to lift, she hadn't had time to request this. She did however like the concept of the Web App and saw it as a useful tool within the care home arena.

Professional in the field of dementia number 3 worked as a social prescriber, and acknowledged the problems created by COVID for people living with dementia, and the lack of face-to-face support.

There has been no social support. It's been difficult. Now there are fears from support groups that they are vulnerable, and they are hesitant about starting up again. Specialist groups aren't going to come back yet, so perhaps people will start going to other groups... like perhaps a yoga group which is dementia friendly. [Professional in the field of dementia 3]

The lack of support given to people with dementia, residing in the community and in care homes during the pandemic is a stark reminder of the struggles which have been apparent, and the continuing threat which Covid-19 poses for the most vulnerable. It is also a reminder of the importance of social engagement for those living with dementia and their care-partners.

Theme 6: Meeting the needs of users

Professional in the field of dementia number 1 spoke of the needs which people living with dementia, and their care-partners who are residing in the community have for information, and the valuable impact which support groups have on their lives.

People in the community have no idea what's going on. They really need to know what's going on. [Professional in the field of dementia 1]

The same participant (Professional in the field of dementia 1) also mentioned that the pandemic had forced so many people to engage with technology, who otherwise would not have done so. She referred to residents in care homes who now relied on technology to keep in touch with their families, commenting:

If we hadn't had technology, we would have been stumped. It really is the way forward. [Professional in the field of dementia 1]

When asked about usability, professional in the field of dementia number 2 said that despite her own computer literacy not being good, she found the Web App easy to use, and the colours to be engaging. She also spoke of the 'digital divide', which refers to the apparent lack of computer skills in older people and referenced some of the specific schemes in Greater Manchester which aimed at connecting older people. She also offered some comments around the planned improvements to the Web App which would be launched when the native app goes live.

I like the idea of a 5-star review system. Sometimes its difficult to rate an activity without being emotional. It's a good indicator of what's gone on, which can be

used to reflect back on someone's experience. [Professional in the field of dementia 2]

Endorsing the Web App, Professional in the field of dementia number 3 felt that the App had potentially far-reaching impacts for people with dementia and their care-partners and will allow them to access factually truthful information. The text also refers to the storing of information, which can later act as a reference point.

It benefits people massively. There is loads of information out there, but this [the app] is the host. Otherwise, how do you read through it all, which bits are true, and which bits are right or wrong. [Professional in the field of dementia 3]

In another comment, Professional in the field of dementia number 3 spoke about the fact that not everyone wanted to focus their lives around dementia, and wanted the normality in their life, where they could do ordinary activities, and retain their own identities.

People don't always want to acknowledge it [Dementia] but this [the app] is nice, its keeping it real... One lady I know said she liked the app because it made me feel like I'm not a carer, because I'm not, I'm his wife. People want to do normal things, not just go to dementia groups... People connect with it because they can connect in their own time. [Professional in the field of dementia 3]

The text reminds us of the complex nature of providing care and support to people with dementia, and that there is not a single approach which fits all needs. The multi-functional nature of the Web App symbolises how it can potentially meet a diverse set of needs, without the stigma which is often attached to dementia.

Theme 7: The Greater moments Web App development.

Asked what features would be useful to her work in care homes, Professional in the field of dementia 1 suggested place-based information, reflecting upon her own experience of caring for her elderly grandmother, and the residents in her care:

To me pictures of Manchester would be interesting. I often take photos so that I can show my Nan, who is 95. She's always interested in history, how areas have changed... For people with dementia that would be amazing, helping them to reminisce... Our lot like a bit of everything. We use pictures and photos. [Professional in the field of dementia 1]

It was also felt by professional in the field of dementia number 1 that when the native app became live and was in a downloadable format, that it would be much less time consuming to use and more beneficial for her, and would like to have some time trialing the new version when it is released.

I'd like to see the app as being 'the digital support in your pocket', almost like a little friend, where you can track how you're feeling. It's a base to store memories and photos, because we know how important that is in dementia care. [Professional in the field of dementia 2]

In the second interview, professional in the field of dementia number 2 had in-depth knowledge of the Greater moments Web App, having previously worked for one of its sponsors, and was eager to promote it because of her positive experience with it. She also felt that there were not enough resources available to support people living with dementia and their care-partners. When asked how she'd like to see the app evolve, Professional in the field of dementia number 2 replied:

I'd like to see it linked to music, as I think music therapy is good for people with dementia. We know this, but do we really? This would tell us... I guess I'd also like to see it more widely used. [Professional in the field of dementia 2]

In the text above the professional in the field number 2 suggests that the Greater moments App could be used as a way of validating interventions aimed at people with dementia, such as music therapy. Professional in the field of dementia 2 also talked about the need for clinicians to engage with the app, as she felt that this was key to its promotion, stating:

If we get more clinicians to use it, who see people with dementia in the community, we could offer it as a service, almost like a quick referral service, so on diagnosis they get the app. [Professional in the field of dementia 2]

It is worth acknowledging here that Social Sense is working Manchester Camerata's Music in Mind programme for example, exploring how Greater Moments can maximise engagement and evaluation potential.

The need to engage practitioners in the use and benefits of using the App was a view shared by Professional in the field of dementia number 1, who also felt that it should be

promoted through education networks, and other professionals working in the field of dementias such as hospices.

*Professional in the field of dementia 3 worked as a **social prescriber**, and also acknowledged the need to promote the app, across a broad field, and said that professionals had started to hear about the app, but not understand its purpose. In her own professional role, she describes how she champions the app in the following text:*

I'm mainly telling people about the app, telling them how to use it, what it will become, and how they can shape it...We need to get the information out there, so people know what's out there... The app has huge potential to know what's out there. You have the sense of being part of a wider community. It's got purpose. If you can rely on something its huge. [Professional in the field of dementia 3]

The interviews with Professional in the field of dementia provided a more holistic view of the app, and the potential which could be realised in the wider community. Whilst from different professional backgrounds, all interviewees felt that the app had great potential, which filled a gap in dementia support by hosting all the information about the local area, which otherwise would be inaccessible to people.

Word cloud

- [faire de meme pour IDo - blog post regarding results](#)
[+ newsletter to share content](#)

The following word cloud summarises some of the comments which have been drawn from the data collection phase, and the evaluators impressions and findings from the text.

Image 5 Word cloud from qualitative analysis



6.0 Quantitative data

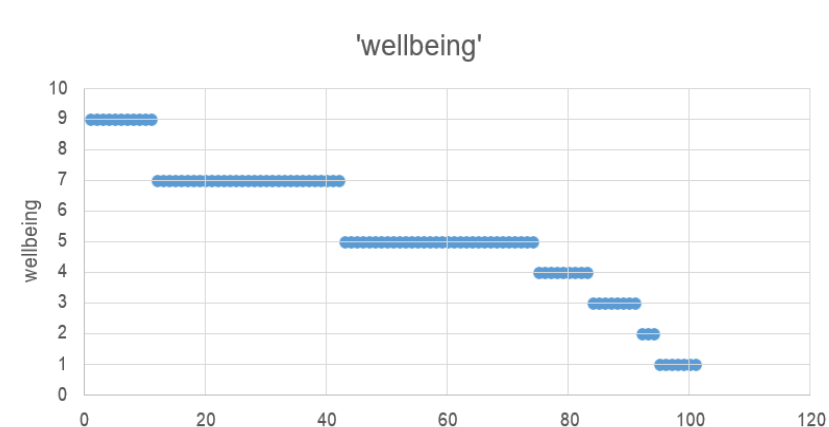
6.1 Wellbeing scores on Greater Moments Web App

The following data illustrates the wellbeing scores taken from the wellbeing sample. The number of users was 40, who together logged 101 wellbeing scores over the evaluated time.

Table 3 Wellbeing sample frequencies

Logged score	Number of times logged in total	Number of times logged twice	Number of times logged 3 x	Number of times logged 4 times	Number of times logged 5 or more
1	7	1			
2	3		1		
3	8	2			
4	9				1
5	32	6	2		1
6	0				
7	31	3		1	2
8	0				
9	11				

Table 4 Wellbeing sample bar chart



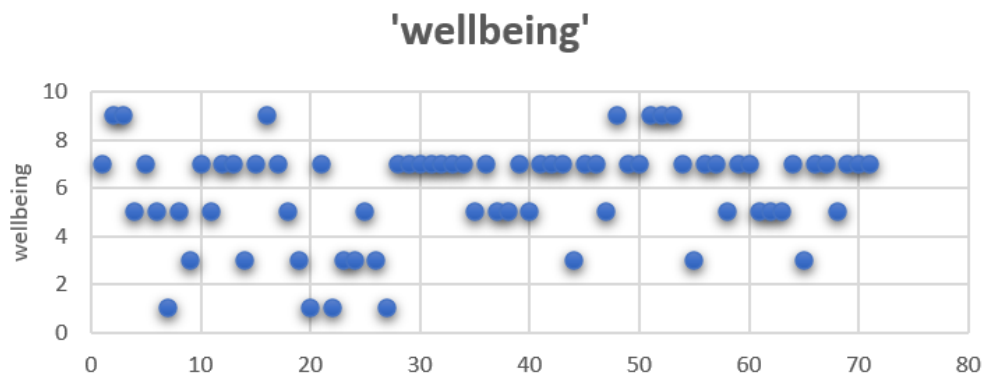
6.2 Wellbeing scores taken from Happening sample

The happening sample had 23 users who logged 72 wellbeing scores logged in.

Table 5 Happening sample wellbeing frequencies

Wellbeing scores	Number of times logged in total	Number of times logged twice	Number of times logged 3 x	Number of times logged 4 times	Number of times logged 5 or more
1	4	1			
2	0				
3	9	1		1	
4	0				
5	16		2		
6	0				
7	35	4	2	1	1
8	0				
9	7	2			

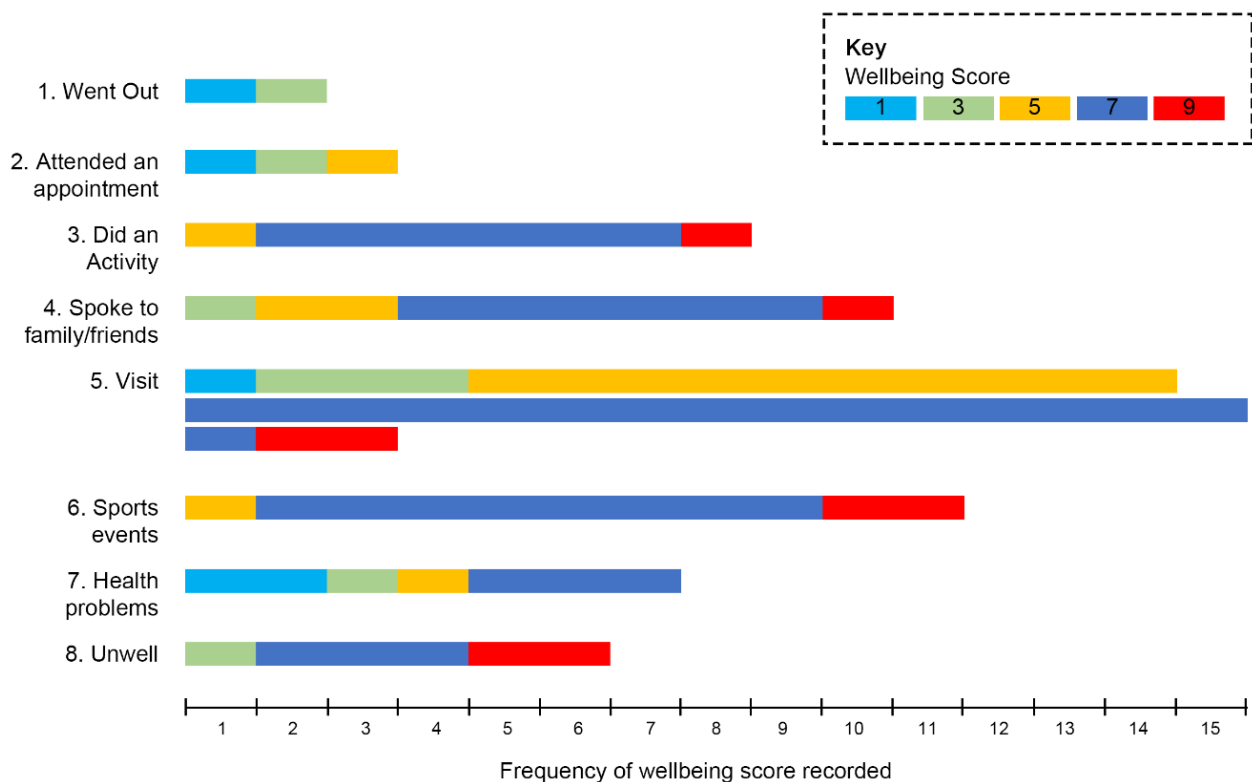
Table 6 Happening sample scatter graph



How 'happenings' impacted upon wellbeing scores

The table below shows how many times, and to what extent that each activity or happening correlates to the individual's wellbeing score. For example, when an individual undertakes a visit, there is a correlation to positive wellbeing, with wellbeing scores logged from 5 to 7 most commonly. However, there are some unusual findings, such as data showing that a person feeling unwell, did not correlate to low feelings of wellbeing. Equally, it may also indicate that when someone has a low wellbeing score (below 3) they may not be motivated to log a wellbeing score, or use the Web App. It will be interesting to see changes in this data when the Web App moves to a native App.

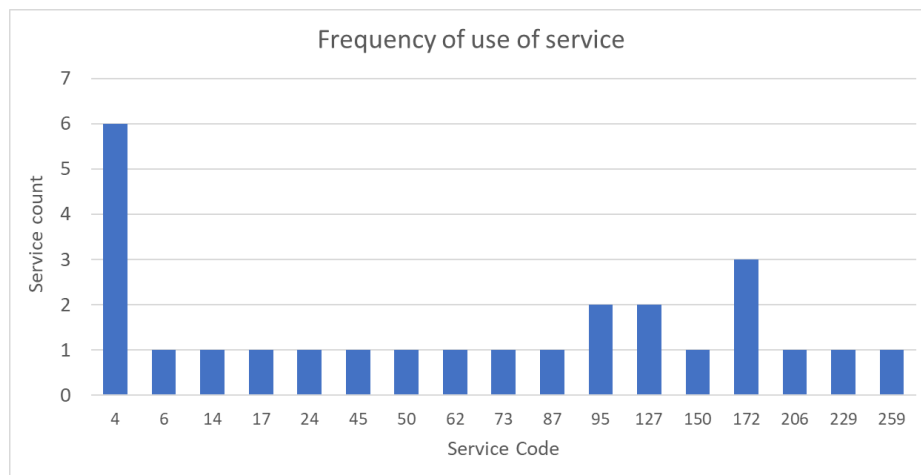
Table 7: Happenings impact on wellbeing



6.3 Evaluation of Services

A unique part of the Greater moments Web App allows people living with dementia, care-partners and paid care-providers to access information on services in their local area. Having visited the event, venue or activity, users are then prompted to rate the service. The following graph demonstrates the frequency in which people have visited individual services.

Table 8 Frequency of service use



The next diagram offers information around how individuals have subjectively rated services, using a score from 1-10, where 10 is excellent and 1 is poor. The current version of the Web App under evaluation does not allow for free text, or for services to be rated in relation to specific characteristics, such as access or facilities etc.

Table 9 Service score by service type



6.4 User feedback short survey

A user survey was carried out in May 2021 whereby all registered users were asked to complete a short survey asking their experiences and usefulness of the Web App. Ten users took part, three were people living with dementia, six were carers and one declined to answer. The responses to all questions are displayed in Appendix 5.

6.5 Long Form Survey data using the DEMQUAL survey

Survey participants were asked to record their feelings in relation to the previous week, answering using a five-point Likert scale. This data can be viewed in Appendix 1 and shows that However, as previously discussed the DEMQUAL survey was designed to assess the wellbeing of people living with dementia. Because the Web App is used by people living with dementia, care-partners, professional carers and champions, it has been problematic to disaggregate data submitted only by those living with dementia from other users. Despite being given information relating to user ID's this did not result in validating the data, since it was clear that some care-partners had attempted to fill this in for the person living with dementia, and therefore this data was excluded from the evaluation as it was deemed to be not subjective ie obtained from the actual person. The evaluation would conclude that unless the DEMQUAL survey can be focused upon those living with dementia, it is felt that this should not be included on the Greater moments App going forward.

7.0 Discussion

This section of the report will briefly look at the findings of this evaluation in relation to the existing body of literature, to draw on any useful parallels which may inform the Greater Moments App development going forward.

7.1 The role of care-partners

Whilst it is appreciated that the role of providing care is generally very rewarding (Stansfeld, 2017) it is also well documented that voluntary care-partners of individuals living with dementia can be under considerable physical, mental and emotional challenges which can lead to poor health outcomes (Cheng, 2017). Indeed, many care-partners are themselves older people, with their own health problems to deal with alongside their caring responsibilities (Farina et al, 2017). Findings from this study demonstrate the challenging nature of caring for someone with dementia, with themes exploring anxiety, frustration and distress. However, it would appear that the Web App

could provide an outlet for some of the anxiety felt by care-partners, by adding journal entries, as 'moments'. It would also be plausible to suggest that recording 'moments' is a rather cathartic intervention, which may help voluntary care-partners to cope with the challenges they encounter, whilst also giving them the opportunity to remember precious times. As Mason (2018) writes, 'moments' are charismatic not because they are measurable fractions of time, but because they are 'multi-sensory glimpses, windows, apertures or revelations' (p.193) into a person's everyday world and lived experience. This is particularly important here, as voluntary care-partners openly share glimpses of their day-to-day lives, which often undergo considerable emotional input.

7.2 The role of professional carers

The Greater Moments Web App was also used by professional carers to enter observations about residents who were living with dementia. Whilst this provided evidence that interventions such as family visits, the butterfly kit, and entertainment sessions improved residents perceived wellbeing, it may also provide a medium with which to record their own wellbeing. In the present version of the Web App, the information, which was inputted by professional carers, may be a duplicated record to existing care plans used in the care home. Supporting this notion, would be the terminology being used in reporting such as 'x was engaged with'. We suggest that there could be positive results in recording professional carers own 'moments', which could promote individuals to become reflective practitioners. This does not mean, as done in many studies, to understand nurses' emotional experiences that the professional carers undertake a structured process of reflection, guided by frameworks and models (eg Johns, 1999). Instead, we propose that professional carers (Registered nurses and care assistants) may benefit from the cathartic nature of recording 'moments', which may be retrospectively used to highlight moments of stress, moments for learning, moments of risk, as well as moments of everyday practice, which are often hidden from 'outsiders' view. Whilst there are existing studies which have used written, paper-based diary research on nurses (For example, Ten Hoeve et al, 2019; Hopia, et al, 2019) an initial scoping exercise has not revealed any research using Apps in care homes, which we contend would be of interest to the research community, as well as workforce planning across the care home sector, which experiences high turnover and poor retention from staff.

The evaluators would also speculate that the current version of the Web App may have been problematic to use in partnership with residents in care homes, and as the native App goes live in the near future, this will have greater usability, as it will be a downloadable App and can then be used on mobile phones and tablet devices. This would allow a more person-centred approach to develop, allowing professional carers the ability to better understand the way in which the person with dementia experiences the world (Kitwood, 1997). The recording of these 'moments' may allow care homes a chance to showcase what Killick (2016:181) suggests as providing as 'much

meaningfulness as possible' by engaging people living with dementia in creative activities.

7.3 Individuals living with dementia

For people living with dementia the Web App offered a valuable opportunity to capture and record moments in real-time, which are considered an important part of preserving a sense of identity and selfhood (Kitwood, 1997, Keady et al, 2020)). Indeed, work by Sabat (2002) conceptualises the importance of retaining a sense of self and concentrating on a persons retained abilities as opposed to the diminution of the person's capabilities. Therefore, it is vital that people living with dementia are supported to live well and be valued as 'effective citizens' (Bartlett et al., 2014:1292) rather than being defined by deficits and limitations (Birt et al., 2017). The Greater moments App also offers the person living with dementia and their care-partners a single point of access, where they can access suggested activities, organisations and networks to engage and connect with. Whilst the present data is limited around services, due to users being unable to visit places/activities, as pandemic restrictions lift this aspect of the App should facilitate civic engagement, whilst helping to make venues, and events more dementia friendly and accessible.

The work of Professor John Keady whilst being inspirational to the development of the Web App, now resonates with the Apps capabilities, and the ways in which people who are living with dementia can go on to have greater moments in the future. By capturing 'moments in time', this allows people to connect with their self, their environment, and other people, including other people living with dementia (Keady et al, 2020).

8.0 Recommendations

This report presents a robust evaluation of the available data generated by the Greater moments Web App. It also offers a critical view of an evolving technology, which has been open to constant change, through its engagement with an advisory group, referred to as 'spotlight sessions' (See section 2.3). This process of co-design has been fundamental to the App's development, and we have witnessed its agile response to the advisory group's ideas and feedback. Throughout the evaluation we have been impressed by the potential which this Application has for individuals living with dementia, their care-partners and those who provide care and support in a professional capacity. We recognise the potential value of the App and believe that the following recommendations can act as a benchmark for its continued development.

1. Build into the native App a tool with which to determine social value/return on investment.

We would recommend that a cost benefit model is devised for future commissioning. We are aware that Social Sense have on other projects been able to determine a social value and Social Return on Investment (SROI) rating and a similar achievement

here could pave the way for more transformational type commissioning. The evaluators are happy to discuss the best way of quantifying benefits, impacts and demonstrating the value of the App.

2. Removal or Individual focus applied to DEMQUAL survey from the Web App

Because the Greater Moments Web App has been used by people living with dementia, care-partners, professional carers and champions, it has been problematic to disaggregate data submitted only by those living with dementia from other users. Despite being given information relating to user ID's this did not result in valid data, since it was clear that some care-partners had attempted to fill this in for the person living with dementia, and therefore this data was excluded from the evaluation as it was deemed to be not subjective or obtained from the actual person. The evaluation would conclude that unless the DEMQUAL survey can be focused upon those living with dementia, it is felt that this should not be included on the Greater moments App going forward.

3. Professional carers to be given the opportunity to record their own subjective wellbeing, to support reflective practice, which would enhance care for people living with dementia.

Presently, the Web App entries made by professional carers, generally in care home environments, are related to resident's wellbeing. Whilst this is important, it appears to be a third person perspective of the resident's experience and wellbeing and conceivably could be a repetition of care notes. This data has a place, and importance, and once developed as a downloadable (native app), available on smart phone and tablet, data could be recorded in partnership with the resident, and create rich experiential insights. However, either collected separately or alongside, we would see a huge potential in giving professional carers their own space to log their feelings/experiences of their role. Existing evidence which has looked at the benefits of keeping diarised accounts of experience in clinical practice, have mainly centred upon registered nurses, working in clinical environments (See example: Munyewende and Rispel, 2014). This method of data collection, and environment would add unique knowledge to the body of literature.

4. Recruitment and mobilisation of Champions

At the time of writing there are currently 12 champions, who hope to drive forward engagement. Whilst without specific data relating to their role, and engagement it is impossible to judge their impact, interviews with service professionals pointed to a need to recruit champions from clinical practice, with the intention of practitioners recommending the Greater Moments app early in the dementia journey, to gain maximum impact for the individual with dementia and their care-partners.

9.0 Next steps

Because of the constant evolvement of the evaluated Web App, it seems appropriate to give a brief synopsis of this development.

On September 13th, 2021 an updated version of the Web App was launched which added many of the features from the spotlight sessions. The web app will continue to be used in a more administrative way, encompassing both PC and tablets to support carers who might want to support multiple users (i.e. within a care home).

Alongside this new version is a 'native' App, which can now be downloaded free of charge from the App Store and Android following a period of closed user testing in August.

The native app is much more focussed on the end user and is more visually interactive, including features such as notification prompts that are not possible in the web version.



The native version has some significant changes and is worthy of note.

The native app features are significantly enhanced compared to the web app. The ongoing consultation has informed this process. Events and activities, as well as personal events can be added to the calendar/the user's calendar. These can be rated, with a five-star system which also offers the user the ability to give further feedback, reviewing the accessibility, how dementia friendly it was and whether they'd recommend it, alongside the option of free text. The moments journal categorises moments and allows the user to add an emoji about how they're feeling, add notes and upload or take an image to add to their moment. Most notably the functionality of the native app allows the user to reflect upon their moments and wellbeing in their own moments journal and dashboard

In combination, the native version should enable a deeper and richer dataset that will support efforts to demonstrate the Health Economics within the next evaluation.

Summary

This evaluation describes the ongoing development of the Greater Moments Web App. It documents how it is being used by people living with dementia, voluntary care partners, and those providing care and support on a professional basis. The App is constantly being updated and functionality refined making this evaluation a 'snap-shot' in its history. Such a technology which has the ability to support people with dementia and their care-partners along the care pathway and in different care settings is of interest to service providers and policy makers. Whilst it has the capacity to support memories and promote social interaction, it also has the potential to improve services, making them more dementia friendly, accessible and safer.

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References

- Alaszewski A. (2006) Using Diaries for Social Research: London, England: SAGE
- All-Party Parliamentary Group on Dementia. (2019). *Hidden no more: Dementia and disability*. Retrieved from: https://www.alzheimers.org.uk/sites/default/files/2019-06/APPG_on_Dementia_2019_report_Hidden_no_more_dementia_and_disability_media.pdf
- Alzheimer's Society. (2014). Dementia UK: Update. Second edition. Alzheimer's Society, London. Retrieved from: https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf
- Alzheimer's Society. (2021) Dementia Friendly Communities [Internet]; Available at: <https://www.alzheimers.org.uk/dementiafriendlycommunities>. [Accessed 6th June, 2021]
- Alzheimer's Association. (2019). 2019 Alzheimer's disease facts and figures. *Alzheimer's & dementia*, 15(3), 321-387.
- Alzheimer's Disease International. (2016) World Alzheimer Report 2016. Improving Healthcare for People with Dementia. London: Alzheimer's Disease International,
- Atkins JL, Masoli JAH, Delgado J, et al. (2020) Preexisting comorbidities predicting COVID-19 and mortality in the UK biobank community cohort. *J Gerontol A Biol Sci Med Sci*;75(11):2224-2230.
- Bartlett, R. (2014). Citizenship in action: the lived experiences of citizens with dementia who campaign for social change. *Disability & Society*, 29(8), 1291-1304.
- Birks, J. (2016). *News and civil society: The contested space of civil society in UK media*. Routledge.
- Birt, L., Poland, F., Csipke, E., & Charlesworth, G. (2017). Shifting dementia discourses from deficit to active citizenship. *Sociology of Health & Illness*, 39(2), 199-211.
- Bowling A, Rowe G, Adams S, et al. Quality of life in dementia: a systematically conducted narrative review of dementia-specific measurement scales. *Aging Ment Health* 2015; 19:13–31.

- Bryden, C. 2005. *Dancing with dementia: My story of living positively with dementia*. London: Jessica Kingsley Publishers.
- Buckner, S., Darlington, N., Woodward, M., Buswell, M., Mathie, E., Arthur, A., Lafortune, L., Killett, A., Mayrhofer, A., Thurman, J., Goodman, C. (2019). Dementia friendly communities in England: A scoping study. *International Journal of Geriatric Psychiatry*, 34(8), 1235-1243.
- Cheng, S. T. (2017). Dementia caregiver burden: a research update and critical analysis. *Current psychiatry reports*, 19(9), 1-8.
- Coffé, H., and Bolzendahl, C. (2011). Civil society and diversity. In *The Oxford handbook of civil society*.
- Daykin, N., Mansfield, L., Payne, A., Kay, T., Meads, C., DInnocenzo, G., Burnett, A., Dolan, P., Julier, G., Longworth, L., Tomlinson, A., Testoni, S. and Victor, C. (2016) What works for wellbeing in culture and sport? Report of a DELPHI process to support coproduction and establish principles and parameters of an evidence review. *Perspectives in Public Health*. Retrieved from: <https://journals.sagepub.com/doi/full/10.1177/1757913916674038>
- Dementia UK. (2020). Facing it alone. <https://www.dementiauk.org/wp-content/uploads/2020/11/Facing-It-Alone.pdf>
- Department of Health. (2009). *Living Well with Dementia: a national dementia strategy*. Department of Health. London
- Department of Health. (2010). *Quality outcomes for people with dementia: Building on the work of the national dementia strategy*. Department of Health. London
- Department of Health. (2011). *Living Well with Dementia: a national dementia strategy - good practice compendium*. Department of Health. London
- Department of Health. (2012). *Prime Minister's challenge on dementia: Delivering major improvements in dementia care and research by 2015*, Department of Health. London
- Department of Health. (2013). *Dementia: A State of the Nation Report on Dementia Care and Support in England*, Department of Health. London
- Department of Health. (2014). *Wellbeing: Why it matters to health policy*. Department of Health. London
- Department of Health. (2015). *Prime Minister's challenge on dementia 2020*. Department of Health. London
- Department of Health (2016). *Prime minister's challenge on dementia 2020: Implementation plan*. Department of Health. London
- Dichter, M. N., Schwab, C. G., Meyer, G., Bartholomeyczik, S., & Halek, M. (2016). Linguistic validation and reliability properties are weak investigated of most dementia-specific quality of life measurements—a systematic review. *Journal of Clinical Epidemiology*, 70, 233-245.

Dowlen, R., Keady, J., Milligan, C., Swarbrick, C., Ponsillo, N., Geddes, L., & Riley, B. (2021). In the moment with music: an exploration of the embodied and sensory experiences of people living with dementia during improvised music-making. *Ageing & Society*, 1-23.

Duff, C. (2018) *Dementia: assessment, management and support for people living with dementia and their carers*. Technical Report. National Institute of Clinical Excellence, London

Farina, N., Page, T. E., Daley, S., Brown, A., Bowling, A., Basset, T., ... & Banerjee, S. (2017). Factors associated with the quality of life of family carers of people with dementia: A systematic review. *Alzheimer's & Dementia*, 13(5), 572-581.

Giebel, C., Hanna, K., Tetlow, H., Ward, K., Shenton, J., Cannon, J., ... & Gabbay, M. (2021). "A piece of paper is not the same as having someone to talk to": accessing post-diagnostic dementia care before and since COVID-19 and associated inequalities. *International Journal for Equity in Health*, 20(1), 1-11.

Gov.UK (2020). Coronavirus (COVID-19) in the UK online: <https://www.gov.uk/guidance/coronavirus-covid-19-information-for-the-public>

Greenwood N, Habibi R, Mackenzie A, et al (2013) Peer support for carers: a qualitative investigation of the experiences of carers and peer volunteers. *Am J Alzheimers Dis Other Dement.*;28(6):617–26.

Hopia, H., Miettinen, S., Miettinen, M., & Heino-Tolonen, T. (2019). The voice of paediatric oncology nurses: A longitudinal diary study of professional development. *European Journal of Oncology Nursing*, 42, 28-35.

Johns, C. (1999). Reflection as empowerment?. *Nursing Inquiry*, 6(4), 241-249.

Keady, J. D., Campbell, S., Clark, A., Dowlen, R., Elvish, R., Jones, L., ... & Williams, S. (2020). Re-thinking and re-positioning 'being in the moment' within a continuum of moments: Introducing a new conceptual framework for dementia studies. *Ageing & Society*, 1-22.

Kelly, F., and Innes, A. (2016). Facilitating independence: The benefits of a post-diagnostic support project for people with dementia. *Dementia*, 15(2), 162-180.

Killick, J. 2016. Creativity and Dementia. In Clarke, C. & Wolverson, E. (eds.), *Positive Psychology Approaches to Dementia*. London: Jessica Kingsley Publishers.

Kitwood, T. 1997. *Dementia reconsidered: the person comes first*. Buckingham, UK: Open University Press.

Kwasky AN, Harrison BE, Whall AL. (2010) Quality of life and dementia: an integrated review of literature. *Alzheimer's Care Today* 2010; 11:186–95

Mason, J. 2018. *Affinities: Potent connections in personal life*. London: John Wiley & Sons

Munyewende, P. O., & Rispel, L. C. (2014). Using diaries to explore the work experiences of primary health care nursing managers in two South African provinces. *Global health action*, 7(1), 25323.

National Institute for Health and Care Excellence 2018. Dementia: assessment, management and support for people living with dementia and their carers. NICE guideline. Published June 2018. Available at: <http://www.nice.org.uk/guidance/ng97>

O'Shea, E., Keogh, F., and Heneghan, C. (2018). Post-Diagnostic support for people with dementia and their carers.

Pickett, J., Bird, C., Ballard, C., Banerjee, S., Brayne, C., Cowan, K., and Walton, C. (2018). A roadmap to advance dementia research in prevention, diagnosis, intervention, and care by 2025. *International journal of geriatric psychiatry*, 33(7), 900-906.

Pinto S, Fumincelli L, Mazzo A, et al. (2017) Comfort, well-being and quality of life: discussion of the differences and similarities among the concepts. *Porto Biomed J* ;2:6–12.

Robertson S, Cooper C, Hoe J, et al. (2017) Proxy rated quality of life of care home residents with dementia: a systematic review. *Int Psychogeriatr* ;29:569–81

Sabat, S.R. (2001). The experience of Alzheimer's disease: Life through a tangled veil. Oxford: Blackwell Publishers

Söylemez, B. A., Küçükgülçü, Ö., Akyol, M. A., & Işık, A. T. (2020). Quality of life and factors affecting it in patients with Alzheimer's disease: a cross-sectional study. *Health and Quality of Life Outcomes*, 18(1), 1-7.

Stansfeld, J., Stoner, C. R., Wenborn, J., Vernooij-Dassen, M., Moniz-Cook, E., & Orrell, M. (2017). Positive psychology outcome measures for family caregivers of people living with dementia: A systematic review. *International psychogeriatrics*, 29(8), 1281-1296.

Szymczynska, P., Innes, A., Forrest, L., and Stark, C. (2010) Diagnostic and post-diagnostic service provision to people with dementia and their carers with particular interest in remote and rural populations. Stirling: University of Stirling.

Ten Hoeve, Y., Kunnen, S., Brouwer, J., & Roodbol, P. F. (2018). The voice of nurses: Novice nurses' first experiences in a clinical setting. A longitudinal diary study. *Journal of clinical nursing*, 27(7-8), e1612-e1626.

Travers C. (2011) Unveiling a reflective diary methodology for exploring the lived experiences of stress and coping. *Journal of Vocational Behavior*.;79:204-216.

Wheatley, A., Bamford, C., Brunskill, G., Booi, L., Dening, K. H., Robinson, L., and PriDem study team. (2021). Implementing post-diagnostic support for people living with dementia in England: a qualitative study of barriers and strategies used to address these in practice. *Age and Ageing*.

WHOQOL Group. (1995). The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. *Social science & medicine*, 41(10), 1403-1409.

Wu YT, Clare L, Jones IR, et al. (2018) Inequalities in living well with dementia—the impact of deprivation on well-being, quality of life and life satisfaction: results from the

improving the experience of dementia and enhancing active life study. *Int J Geriatr Psychiatry*;33(12):1736–42.

10.0 Appendices

Appendix 1: Long form survey results

Long Form Survey – Greater Moments Web App

For all the questions I'm going to ask you, I want you to think about the last week. First I'm going to ask about your feelings. In the last week, have you felt...

1. Cheerful?

1. A lot	186(12-11-20) : 318(02/03/21) : 332(12/02/21) : 338(18/02/21) : 380(19/04/21) : 383(23/04/21) : 418(26/05/21)	7
2. Quite a bit	184(11-11-20) : 186(02-11-20) : 241(08/07/2021) : 283(08-01-21) : 330(09-02-21) : 342c(21/05/21) : 342b(21/05/21) : 349(24/02/21) : 361(21/07/21) : 414b(11/05/21) : 414a(11/05/21) : 480(26/07/21) : 488(14/07/21)	13
3. A little	184(09-06-21), 184(20-12-20) : 201a(10-11-20) : 201b(10-11-20) : 248b(20-12-20) : 248a(20-12-20) : 283(18-01-21) : 342a(21/05/21) : 442(21/06/21)	9
4. Not at all	492(12/07/21)	1

2. Worried Or Anxious?

1. A lot	: 201b(10-11-20) : 480(26/07/21)	2
2. Quite a bit	186(12-11-20) : 201a(10-11-20) : 248b(20-12-20) : 283(18-01-21) : 283(08-01-21) : 414b(11/05/21) : 414a(11/05/21)	7
3. A little	184(09-06-21), 184(20-12-20) : 186(02-11-20) : 241(08/07/2021) : 248a(20-12-20) : 318(02/03/21) : 330(09-02-21) : 332(12/02/21) : 338(18/02/21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 349(24/02/21) : 383(23/04/21) : 418(26/05/21) : 442(21/06/21)	16
4. Not at all	184(11-11-20) : 361(21/07/21) : 380(19/04/21) : 492(12/07/21)	4

3. That You Are Enjoying Life?

1. A lot	: 342c(21/05/21) : 342a(21/05/21) : 380(19/04/21) : 418(26/05/21)	4
2. Quite a bit	184(20-12-20) : 186(12-11-20) : 186(02-11-20) : 241(08/07/2021) : 248b(20-12-20) : 248a(20-12- 20) : 283(18-01-21) : 332(12/02/21) : 338(18/02/21) : 342b(21/05/21) : 349(24/02/21) : 383(23/04/21) : 414a(11/05/21) : 480(26/07/21) : 488(14/07/21)	15
3. A little	184(09-06-21) : 184(11-11-20) : 201a(10-11-20) : 201b(10-11-20) : 318(02/03/21) : 330(09-02-21) : 361(21/07/21) : 414b(11/05/21) : 442(21/06/21) : 492(12/07/21)	10
4. Not at all	283(08-01-21)	1

4. Frustrated?

1. A lot	283(08-01-21)	1
2. Quite a bit	201a(10-11-20) : 248b(20-12-20) : 283(18-01-21) : 414a(11/05/21) : 480(26/07/21)	5
3. A little	184(09-06-21) : 184(20-12-20) : 184(11-11-20) : 186(12-11-20) : 186(02-11-20) : 241(08/07/2021) : 248a(20-12-20) : 330(09-02-21) : 332(12/02/21) : 338(18/02/21) : 342c(21/05/21) : 361(21/07/21) : 414b(11/05/21) : 488(14/07/21)	14
4. Not at all	201b(10-11-20) : 318(02/03/21) : 342b(21/05/21) : 342a(21/05/21) : 349(24/02/21) : 380(19/04/21) : 383(23/04/21) : 418(26/05/21) : 442(21/06/21) : 492(12/07/21)	10

5. Confident?

1. A lot	186(02-11-20) : 318(02/03/21) : 338(18/02/21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 442(21/06/21)	7
2. Quite a bit	184(20-12-20) : 184(11-11-20) : 241(08/07/2021) : 283(18-01-21) : 330(09-02-21) : 332(12/02/21) : 361(21/07/21) : 380(19/04/21) : 383(23/04/21) : 414b(11/05/21) : 414a(11/05/21) : 418(26/05/21) : 488(14/07/21)	13
3. A little	184(09-06-21) : 186(12-11-20) : 201a(10-11-20) : 201b(10-11-20) : 248a(20-12-20) : 349(24/02/21) : 480(26/07/21)	7
4. Not at all	: 248b(20-12-20) : 283(08-01-21) : 492(12/07/21)	3

6. Full Of Energy?

1. A lot		0
2. Quite a bit	184(20-12-20) : 184(11-11-20) : 186(12-11-20) : 186(02-11-20) : 241(08/07/2021) : 283(18-01-21) : 330(09-02-21) : 332(12/02/21) : 338(18/02/21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 349(24/02/21) : 361(21/07/21) : 380(19/04/21) : 383(23/04/21) : 414b(11/05/21) : 414a(11/05/21) : 418(26/05/21) : 488(14/07/21)	20
3. A little	184(09-06-21) : 318(02/03/21) : 442(21/06/21) : 480(26/07/21)	4
4. Not at all	201a(10-11-20) : 201b(10-11-20) : 248b(20-12-20) : 248a(20-12-20) : 283(08-01-21) : 492(12/07/21)	6

7. Sad?

1. A lot	283(08-01-21)	1
2. Quite a bit	201a(10-11-20) : 201b(10-11-20) : 361(21/07/21)	3
3. A little	184(09-06-21) : 186(12-11-20) : 248b(20-12-20) : 248a(20-12-20) : 283(18-01-21) : 332(12/02/21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 349(24/02/21) : 414b(11/05/21) : 414a(11/05/21) : 418(26/05/21) : 442(21/06/21) : 480(26/07/21) : 492(12/07/21)	16
4. Not at all	184(20-12-20) : 184(11-11-20) : 186(02-11-20) : 241(08/07/2021) : 318(02/03/21) : 330(09-02-21) : 338(18/02/21) : 380(19/04/21) : 383(23/04/21) : 488(14/07/21)	10

8. Lonely?

1. A lot	283(08-01-21)	1
2. Quite a bit	283(18-01-21)	1
3. A little	201a(10-11-20) : 201b(10-11-20) : 241(08/07/2021) : 248b(20-12-20) : 330(09-02-21) : 349(24/02/21) : 414b(11/05/21) : 414a(11/05/21) : 480(26/07/21) : 488(14/07/21) : 492(12/07/21)	11
4. Not at all	184(09-06-21), 184(20-12-20) : 184(11-11-20) : 186(12-11-20) : 186(02-11-20) : 248a(20-12-20) : 318(02/03/21) : 332(12/02/21) : 338(18/02/21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 361(21/07/21) : 380(19/04/21) : 383(23/04/21) : 418(26/05/21) : 442(21/06/21)	17

9. Distressed

1. A lot	283(08-01-21)	1
2. Quite a bit	201a(10-11-20) : 201b(10-11-20) : 480(26/07/21)	3
3. A little	184(09-06-21) , 184(20-12-20) : 248b(20-12-20) : 283(18-01-21) : 342a(21/05/21) : 442(21/06/21) : 488(14/07/21) : 492(12/07/21)	8
4. Not at all	184(11-11-20) : 186(02-11-20) : 241(08/07/2021) : 248a(20-12-20) : 318(02/03/21) : 330(09-02-21) : 332(12/02/21) : 338(18/02/21) : 342c(21/05/21) : 342b(21/05/21) : 349(24/02/21) : 361(21/07/21) : 380(19/04/21) : 383(23/04/21) : 414b(11/05/21) : 414a(11/05/21) : 418(26/05/21)	17

10. Lively?

1. A lot	418(26/05/21)	1
2. Quite a bit	184(20-12-20) : 186(02-11-20) : 283(18-01-21) : 318(02/03/21) : 330(09-02-21) : 332(12/02/21) : 338(18/02/21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 349(24/02/21) : 361(21/07/21) : 380(19/04/21) : 383(23/04/21) : 414b(11/05/21) : 442(21/06/21) : 488(14/07/21)	17
3. A little	184(09-06-21) : 184(11-11-20) : 186(12-11-20) : 201b(10-11-20) : 241(08/07/2021) : 414a(11/05/21) : 480(26/07/21) : 492(12/07/21)	8
4. Not at all	201a(10-11-20) : 248b(20-12-20) : 248a(20-12-20) : 283(08-01-21)	4

11. Irritable?

1. A lot	283(08-01-21) : 318(02/03/21)	2
2. Quite a bit	201a(10-11-20) : 283(18-01-21) : 361(21/07/21) : 414a(11/05/21)	4
3. A little	184(09-06-21) , 184(20-12-20) : 184(11-11-20) : 186(12-11-20) : 186(02-11-20) : 201b(10-11-20) : 241(08/07/2021) : 248a(20-12-20) : 330(09-02-21) : 338(18/02/21) : 349(24/02/21) : 414b(11/05/21) : 480(26/07/21) : 488(14/07/21) : 492(12/07/21)	15
4. Not at all	248b(20-12-20) : 332(12/02/21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 380(19/04/21) : 383(23/04/21) : 418(26/05/21) : 442(21/06/21)	9

12. Fed-up?

1. A lot	184(11-11-20) : 283(18-01-21)	2
2. Quite a bit	201a(10-11-20) : 201b(10-11-20) : 283(08-01-21) : 318(02/03/21) : 492(12/07/21)	5
3. A little	184(09-06-21) , 184(20-12-20) : 186(12-11-20) : 186(02-11-20) : 241(08/07/2021) : 248b(20-12-20) : 248a(20-12-20) : 330(09-02-21) : 332(12/02/21) : 342b(21/05/21) : 342a(21/05/21) : 349(24/02/21) : 361(21/07/21) : 414b(11/05/21) : 414a(11/05/21) : 418(26/05/21) : 442(21/06/21) : 480(26/07/21) : 488(14/07/21)	19
4. Not at all	338(18/02/21) : 342c(21/05/21) : 380(19/04/21) : 383(23/04/21)	4

13. That There Are Things That You Wanted To Do But Couldn't?

1. A lot	186(02-11-20) : 201a(10-11-20) : 201b(10-11-20) : 248a(20-12-20) : 283(08-01-21)	5
2. Quite a bit	184(09-06-21) : 184(11-11-20) : 186(12-11-20) : 248b(20-12-20) : 318(02/03/21) : 330(09-02-21) : 342a(21/05/21) : 414b(11/05/21) : 480(26/07/21)	9
3. A little	184(20-12-20) : 283(18-01-21) : 332(12/02/21) : 338(18/02/21) : 342c(21/05/21) : 342b(21/05/21) : 349(24/02/21) : 380(19/04/21) : 383(23/04/21) : 414a(11/05/21) : 442(21/06/21) : 488(14/07/21) : 492(12/07/21)	13
4. Not at all	241(08/07/2021) : 361(21/07/21) : 418(26/05/21)	3

Next, I'm going to ask you about your memory. In the last week, how worried have you been about...

14. forgetting things that happened recently?

1. A lot	184(09-06-21) : 201a(10-11-20) : 201b(10-11-20) : 248a(20-12-20) : 283(08-01-21) : 480(26/07/21)	6
2. Quite a bit	184(20-12-20) : 248b(20-12-20) : 318(02/03/21)	3
3. A little	184(11-11-20) : 330(09-02-21) : 338(18/02/21) : 349(24/02/21) : 361(21/07/21) : 383(23/04/21) : 442(21/06/21) : 488(14/07/21)	8
4. Not at all	186(12-11-20) : 186(02-11-20) : 241(08/07/2021) : 283(18-01-21) : 332(12/02/21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 380(19/04/21) : 414b(11/05/21) : 414a(11/05/21) : 492(12/07/21)	12

15. forgetting who people are?

1. A lot	283(08-01-21)	1
2. Quite a bit	184(20-12-20) : 201a(10-11-20) : 201b(10-11-20) : 248b(20-12-20) : 283(18-01-21) : 318(02/03/21) : 480(26/07/21)	7
3. A little	184(09-06-21) : 184(11-11-20) : 248a(20-12-20) : 338(18/02/21) : 488(14/07/21)	5
4. Not at all	: 186(12-11-20) : 186(02-11-20) : 241(08/07/2021) : 330(09-02-21) : 332(12/02/21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 349(24/02/21) : 361(21/07/21) : 380(19/04/21) : 383(23/04/21) : 414b(11/05/21) : 414a(11/05/21) : 442(21/06/21) : 492(12/07/21)	16

16. forgetting what day it is?

1. A lot	184(09-06-21) : 201b(10-11-20) : 283(08-01-21)	3
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2. Quite a bit	184(11-11-20) : 201a(10-11-20) : 248b(20-12-20) : 248a(20-12-20) : 283(18-01-21) : 318(02/03/21) : 349(24/02/21) : 480(26/07/21)	8
3. A little	184(20-12-20) : 338(18/02/21) : 488(14/07/21)	3
4. Not at all	186(12-11-20) : 186(02-11-20) : 241(08/07/2021) : 330(09-02-21) : 332(12/02/21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 361(21/07/21) : 380(19/04/21) : 383(23/04/21) : 414b(11/05/21) : 414a(11/05/21) : 442(21/06/21) : 492(12/07/21)	15

17. your thoughts being muddled?

1. A lot	184(09-06-21) : 201a(10-11-20) : 201b(10-11-20) : 248a(20-12-20) : 283(08-01-21)	5
2. Quite a bit	186(12-11-20) : 283(18-01-21) : 480(26/07/21)	3
3. A little	184(20-12-20) : 184(11-11-20) : 248b(20-12-20) : 330(09-02-21) : 349(24/02/21) : 488(14/07/21)	6
4. Not at all	186(02-11-20) : 241(08/07/2021) : 318(02/03/21) : 332(12/02/21) : 338(18/02/21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 361(21/07/21) : 380(19/04/21) : 383(23/04/21) : 414b(11/05/21) : 414a(11/05/21) : 442(21/06/21) : 492(12/07/21)	15

18. difficulty making decisions?

1. A lot	184(09-06-21) : 201b(10-11-20) : 248b(20-12-20) : 248a(20-12-20) : 283(08-01-21)	5
2. Quite a bit	184(11-11-20) : 186(12-11-20) : 201a(10-11-20) : 283(18-01-21) : 480(26/07/21)	5
3. A little	184(20-12-20) : 318(02/03/21) : 338(18/02/21) : 349(24/02/21) : 488(14/07/21)	5
4. Not at all	186(02-11-20) : 241(08/07/2021) : 330(09-02-21) : 332(12/02/21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 361(21/07/21) : 380(19/04/21)	14
	: 383(23/04/21) : 414b(11/05/21) : 414a(11/05/21) : 442(21/06/21) : 492(12/07/21)	

19. poor concentration?

1. A lot	201a(10-11-20) : 201b(10-11-20) : 248a(20-12-20) : 283(18-01-21) : 283(08-01-21)	5
2. Quite a bit	184(09-06-21) : 184(11-11-20) : 186(12-11-20) : 248b(20-12-20) : 480(26/07/21)	5
3. A little	184(20-12-20) : 318(02/03/21) : 330(09-02-21) : 332(12/02/21) : 338(18/02/21) : 361(21/07/21) : 383(23/04/21) : 414a(11/05/21) : 442(21/06/21) : 488(14/07/21)	10

4. Not at all	186(02-11-20) : 241(08/07/2021) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 349(24/02/21) : 380(19/04/21) : 414b(11/05/21) : 492(12/07/21)	9
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Now, I'm going to ask you about your everyday life. In the last week, how worried have you been about...

20. not having enough company?

1. A lot	283(18-01-21) : 283(08-01-21) : 480(26/07/21)	3
2. Quite a bit	201b(10-11-20) : 318(02/03/21) : 492(12/07/21)	3
3. A little	184(20-12-20) : 186(02-11-20) : 201a(10-11-20) : 248b(20-12-20) : 248a(20-12-20) : 332(12/02/21) : 338(18/02/21) : 342c(21/05/21) : 349(24/02/21) : 414b(11/05/21) : 414a(11/05/21) : 488(14/07/21)	12
4. Not at all	184(09-06-21) : 184(11-11-20) : 186(12-11-20) : 241(08/07/2021) : 330(09-02-21) : 342b(21/05/21) : 342a(21/05/21) : 361(21/07/21) : 380(19/04/21) : 383(23/04/21) : 442(21/06/21)	11

21. how you get on with people close to you?

1. A lot	184(09-06-21) : 184(20-12-20) : 184(11-11-20) : 248a(20-12-20) : 283(18-01-21) : 332(12/02/21) : 342a(21/05/21) : 442(21/06/21)	8
2. Quite a bit	480(26/07/21)	1
3. A little	186(12-11-20) : 201a(10-11-20) : 201b(10-11-20) : 248b(20-12-20) : 283(08-01-21) : 318(02/03/21) : 338(18/02/21)	7
4. Not at all	186(02-11-20) : 241(08/07/2021) : 330(09-02-21) : 342c(21/05/21) : 342b(21/05/21) : 349(24/02/21) : 361(21/07/21) : 380(19/04/21) : 383(23/04/21) : 414b(11/05/21) : 414a(11/05/21) : 488(14/07/21) : 492(12/07/21)	13

22. getting the affection that you want?

1. A lot	184(09-06-21) , 184(20-12-20) : 248a(20-12-20) : 283(18-01-21) : 332(12/02/21)	5
2. Quite a bit	318(02/03/21) : 480(26/07/21)	2
3. A little	184(11-11-20) : 201a(10-11-20) : 201b(10-11-20) : 338(18/02/21) : 383(23/04/21) : 488(14/07/21)	6

4. Not at all	186(12-11-20) : 186(02-11-20) : 241(08/07/2021) : 248b(20-12-20) : 283(08-01-21) : 330(09-02-21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 349(24/02/21) : 361(21/07/21) : 380(19/04/21) : 414b(11/05/21) : 414a(11/05/21) : 442(21/06/21) : 492(12/07/21)	16
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23. people not listening to you?

1. A lot	283(18-01-21)	1
2. Quite a bit	184(20-12-20) : 380(19/04/21) : 480(26/07/21) : 492(12/07/21)	4
3. A little	184(09-06-21) : 201a(10-11-20) : 201b(10-11-20) : 248a(20-12-20) : 283(08-01-21) : 332(12/02/21) : 338(18/02/21) : 442(21/06/21)	8
4. Not at all	184(11-11-20) : 186(12-11-20) : 186(02-11-20) : 241(08/07/2021) : 248b(20-12-20) : 318(02/03/21) : 330(09-02-21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 349(24/02/21) : 361(21/07/21) : 383(23/04/21) : 414b(11/05/21) : 414a(11/05/21) : 488(14/07/21)	16

24. making yourself understood?

1. A lot	248b(20-12-20) : 248a(20-12-20) : 283(18-01-21) : 332(12/02/21)	4
2. Quite a bit	492(12/07/21)	1
3. A little	184(09-06-21) , 184(20-12-20) : 186(12-11-20) : 201a(10-11-20) : 201b(10-11-20) : 318(02/03/21) : 338(18/02/21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 349(24/02/21) : 480(26/07/21) : 488(14/07/21)	13
4. Not at all	184(11-11-20) : 186(02-11-20) : 241(08/07/2021) : 283(08-01-21) : 330(09-02-21) : 361(21/07/21) :	11
	380(19/04/21) : 383(23/04/21) : 414b(11/05/21) : 414a(11/05/21) : 442(21/06/21)	

25. getting help when you need it?

1. A lot	283(18-01-21) : 332(12/02/21)	2
2. Quite a bit	248a(20-12-20) : 318(02/03/21) : 480(26/07/21) : 492(12/07/21)	4
3. A little	184(09-06-21) : 201a(10-11-20) : 248b(20-12-20) : 338(18/02/21) : 342a(21/05/21) : 349(24/02/21)	6

4. Not at all	184(20-12-20) : 184(11-11-20) : 186(12-11-20) : 186(02-11-20) : 201b(10-11-20) : 241(08/07/2021) : 283(08-01-21) : 330(09-02-21) : 342c(21/05/21) : 342b(21/05/21) : 361(21/07/21) : 380(19/04/21) : 383(23/04/21) : 414b(11/05/21) : 414a(11/05/21) : 442(21/06/21) : 488(14/07/21)	17
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26. getting to the toilet in time?

1. A lot	248b(20-12-20) : 248a(20-12-20) : 283(18-01-21) : 332(12/02/21) : 480(26/07/21) : 492(12/07/21)	6
2. Quite a bit	283(08-01-21)	1
3. A little	184(09-06-21) : 184(11-11-20) : 201a(10-11-20) : 201b(10-11-20) : 318(02/03/21) : 338(18/02/21) : 349(24/02/21)	7
4. Not at all	184(20-12-20) : 186(12-11-20) : 186(02-11-20) : 241(08/07/2021) : 330(09-02-21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 361(21/07/21) : 380(19/04/21) : 383(23/04/21) : 414b(11/05/21) : 414a(11/05/21) : 442(21/06/21) : 488(14/07/21)	15

27. how you feel in yourself?

1. A lot	283(18-01-21) : 332(12/02/21)	2
2. Quite a bit	184(20-12-20) : 201a(10-11-20) : 201b(10-11-20) : 248b(20-12-20) : 480(26/07/21)	5
3. A little	184(09-06-21) : 184(11-11-20) : 186(12-11-20) : 248a(20-12-20) : 283(08-01-21) : 318(02/03/21) : 338(18/02/21) : 349(24/02/21) : 361(21/07/21) : 492(12/07/21)	10
4. Not at all	186(02-11-20) : 241(08/07/2021) : 330(09-02-21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 380(19/04/21) : 383(23/04/21) : 414b(11/05/21) : 414a(11/05/21) : 488(14/07/21)	11

28. your health overall?

1. A lot	184(20-12-20) : 201a(10-11-20) : 248a(20-12-20) : 283(18-01-21) : 332(12/02/21)	5
2. Quite a bit	201b(10-11-20) : 248b(20-12-20) : 480(26/07/21)	3
3. A little	184(09-06-21) : 186(12-11-20) : 186(02-11-20) : 241(08/07/2021) : 283(08-01-21) : 318(02/03/21) : 330(09-02-21) : 338(18/02/21) : 383(23/04/21) : 414a(11/05/21) : 442(21/06/21) : 488(14/07/21) : 492(12/07/21)	13
4. Not at all	184(11-11-20) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 349(24/02/21) : 361(21/07/21) : 380(19/04/21) : 414b(11/05/21)	8

We've already talked about lots of things: your feelings, memory, and everyday life. Thinking about all these things in the last week, how would you rate...

29. your quality of life overall?

1. Very good	186(02-11-20) : 318(02/03/21) : 332(12/02/21) : 338(18/02/21) : 361(21/07/21) : 380(19/04/21)	6
2. Good	184(20-12-20) : 184(11-11-20) : 186(12-11-20) : 241(08/07/2021) : 248a(20-12-20) : 330(09-02-21) : 342c(21/05/21) : 342b(21/05/21) : 342a(21/05/21) : 349(24/02/21) : 383(23/04/21) : 414b(11/05/21) : 414a(11/05/21) : 442(21/06/21) : 480(26/07/21) : 488(14/07/21)	16
3. Fair	184(09-06-21) : 201a(10-11-20) : 201b(10-11-20) : 248b(20-12-20) : 492(12/07/21)	5
4. Poor	283(18-01-21) : 283(08-01-21)	2

Appendix 2: Interview guide for the evaluation of the Greater MomentsWeb App

Purpose

- Evaluate the efficacy of the app
- Is the app delivering a solution?
- Does the app increase awareness of services and events?

Phone/video call interviews with:

- People living with dementia (carers to facilitate/support?)
- Carers (unwaged and waged)
- Champions
- Professionals in the field of dementia

Options for respondents:

- Phone call
- Video call with carer/cared for – SSL to ask the questions (record the zoom)
- Video call with carer asking the questions and recorded
- Carer to video them asking the questions and send to SSL
- Virtual coffee morning – for PLWD and carers
- Call/video call/virtual coffee morning for professionals

Join us for a brew and chat about the Greater Moments app (send brew packs out to attendees ahead of session)

*Carer to have the questions ahead of the interview

Check they are happy to use the word 'dementia' during the interview (prior to interview)

1. What are their experiences of the app / how do you use it? (which features, how often etc)
2. How did they find out about the app (also use the sign up form data as supplementary)
3. What would you like to see on the app?
4. Useability – how easy is the app to use? Did you need help? What do you need to make it easier for you?
5. How useful was the app during covid and lockdowns? What other support did you have during covid?
6. Ratings – how have / would you use these? What would be useful for people to rate?
7. How has the app impacted your life / lives of those around you (that you care for or support) – created connections? Provided info? Using journal?
Events/services/activities

8. Other than the app where have you or would you find out about activities, services and events?

What motivates people to get involved?

Anything else you'd like to say about the app?

Appendix 3: Sample consent form used by SocialSense in conducting all interviews connected with the evaluation of the Greater Moments App.

Title of Project: **Greater Moments – Brew Box Coffee Morning**

Name of Interviewer:

Please initial or put an 'x' in all boxes

1. I understand this study is voluntary. I am free to withdraw from part or all of this study at any time. I don't need to give any reason. My legal rights won't be affected ☐
2. I understand that I can ask for anything I say to be removed up to one week (7 days) after the interview takes place.
3. I understand that the data collected may be looked at by other people working on this project plus regulatory authorities. I give permission for this. ☐
4. I understand that the data collected may be used to support other research in the future and may be shared anonymously with other researchers.
5. I understand and agree that my words may be quoted anonymously in research outputs. ☐
6. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person
taking consent.

Date

Signature

Appendix 4: User feedback survey of Greater moments Web App

We want your say! Please let us know what you think of the Greater Moments app by filling out this short survey. May 2021 CLOSED

1. Page 1

1. I am a:				
Answer Choices			Response Percent	Response Total
1	Person living with dementia		33.33%	3
2	Carer		66.67%	6
3	Other (please specify):		0.00%	0
			answered	9
			skipped	1
Other (please specify): (0)				
No answers found.				

2. Where in Greater Manchester are you from?				
Answer Choices			Response Percent	Response Total
1	Bolton		30.00%	3
2	Bury		10.00%	1
3	Stockport		0.00%	0
4	Salford		10.00%	1
5	Trafford		0.00%	0
6	Tameside		0.00%	0
7	Manchester		10.00%	1
8	Oldham		0.00%	0
9	Rochdale		0.00%	0
10	Wigan		40.00%	4
			answered	10
			skipped	0





3. How did you find out about the app?			
Answer Choices		Response Percent	Response Total
1	Open-Ended Question	0.00%	0

3. How did you find out about the app?





No answers found.

answered	0
skipped	10

4. How long have you been using the Greater Moments app?



Answer Choices			Response Percent	Response Total
1	0-1 Month		30.00%	3
2	2-3 Months		20.00%	2
3	4-5 Months		20.00%	2
4	5 Months+		30.00%	3
			answered	10
			skipped	0

5. How often do you use the Greater Moments app? (per week)

Answer Choices			Response Percent	Response Total
1	1-5 Times a week		70.00%	7
2	6-10 Times a week		10.00%	1
3	11-15 Times a week		10.00%	1
4	15+ Times a week		10.00%	1
			answered	10
			skipped	0

2. Page 2






6. How well does the Greater Moments app meet your needs?

Answer Choices			Response Percent	Response Total
1	Not at all		0.00%	0
2	Adequately (satisfactory)		0.00%	0
3	Well		50.00%	1
4	Very well		50.00%	1


6. How well does the Greater Moments app meet your needs?

	answered	2
	skipped	8

7. Which 3 features are the most valuable to you? (Please tick 3 features from the list below)

Answer Choices			Response Percent	Response Total
1	Recording Wellbeing		50.00%	1
2	Services		100.00%	2
3	Events		50.00%	1
4	Service and Event Ratings		100.00%	2
5	Calendar		50.00%	1
6	Recording of moments		0.00%	0
			answered	2
			skipped	8

8. Which app feature do you use most often in your day-to-day? (Please tick one feature from the list below)

Answer Choices			Response Percent	Response Total
1	Recording Wellbeing		0.00%	0
2	Services		0.00%	0
3	Events		100.00%	2
4	Service and Event Ratings		0.00%	0
5	Calendar		0.00%	0
6	Recording of moments		0.00%	0
			answered	2
			skipped	8

9. On a scale of 1-10 how well would you rate your experience when navigating around the Greater Moments app?(When 1 = Not very good and 10 = Very good)

Item	Average	Min	Max	Std. Deviation	Total Responses
1	9.00	8.00	10.00	1.00	2
				answered	2
				skipped	8



9. On a scale of 1-10 how well would you rate your experience when navigating around the Greater Moments app?(When 1 = Not very good and 10 = Very good)

Item	Average	Min	Max	Std. Deviation	Total Responses
Comments: (1)					
1	01/01/1900 00:00 AM ID: 0				

What is your favourite thing about the Greater Moments app?

Answer Choices			Response Percent	Response Total
1	Open-Ended Question		100.00%	2
1	21/04/2021 19:57 PM ID: 164867030	I like seeing what's available and different activities. Hoping to get more out of it as everywhere opens up and more activities become available		
2	30/04/2021 16:48 PM ID: 165588558	nothing		
			answered	2
			skipped	8

10. Is there anything you would change about the Greater Moments app?





Answer Choices			Response Percent	Response Total
1	Yes		0.00%	0
2	No		50.00%	1
3	If yes (please specify):		50.00%	1
			answered	2
			skipped	8
If yes (please specify): (1)				
1	21/04/2021 19:57 PM ID: 164867030	Maybe add pics of cared for enjoying activities. Also 9f people have been to different places, they could advise on how dementia friendly it was, wheelchair friendly, hilly etc		

How has the app impacted your life or the lives of those around you?			
Answer Choices			Response Percent
			Response Total
1	Open-Ended Question		100.00%
	1	21/04/2021 19:57 PM ID: 164867030 We have joined in and enjoyed zooms which we found out about on the app	1
			answered
			skipped





Appendix 5 Short survey data

The following data relates to the short form survey



The following table shows how long individuals had been using the Web App.

Answer Choices			Response Percent	Response Total
1	0-1 Month		30.00%	3
2	2-3 Months		20.00%	2
3	4-5 Months		20.00%	2
4	5 Months+		30.00%	3






Seven of the users stated that they were using the Web App between 1-5 times a week, with others ranging to as much as fifteen times a week, as seen in the following table.

Answer Choices		Response Percent	Response Total
1-5 Times a week		70.00%	7
6-10 Times a week		10.00%	1
11-15 Times a week		10.00%	1
15+ Times a week		10.00%	1

Asked to rate how well the Greater Moments Web App met their needs, only two responses were given, with one person stating that it met their needs well, and the other stating it met their needs very well.

1	Not at all		0.00%	0
2	Adequately (satisfactory)		0.00%	0
3	Well		50.00%	1
4	Very well		50.00%	1

Users were asked to rate the 3 features which they felt were the most valuable to them. Only two responses to this question were given, showing that the services and rating of services were felt to be the most important. See data chart below. Neither user rated the recording of moments to be the most valued feature.

Recording Wellbeing		50.00%	1
Services		100.00%	2
Events		50.00%	1
Service and Event Ratings		100.00%	2
Calendar		50.00%	1
Recording of moments		0.00%	0

The survey asked which Web App feature do you use most often in your day-to-day life. Only two responses were submitted, and both users responded to the question stating the 'events' feature to be the most used. When given the opportunity to offer their own perspectives on their favourite thing about the Web App, only two responses were submitted.

Response 1: 'I like seeing what's available and different activities. Hoping to get more out of it as everywhere opens up and more activities become available'

Response 2: 'Nothing'

The final question asked if users would like to change anything about the Web App. Only two responses were submitted. One user responded no, there would be nothing they wanted to change, and the other responded that they would like to see changes, adding

Response 1: Maybe add pics of cared for enjoying activities. Also if people have been to different places, they could advise on how dementia friendly it was, wheelchair friendly, hilly etc

Appendix 6 App functionality

The following illustrations relate to the functionality of the Native App:

1. Welcome Screen

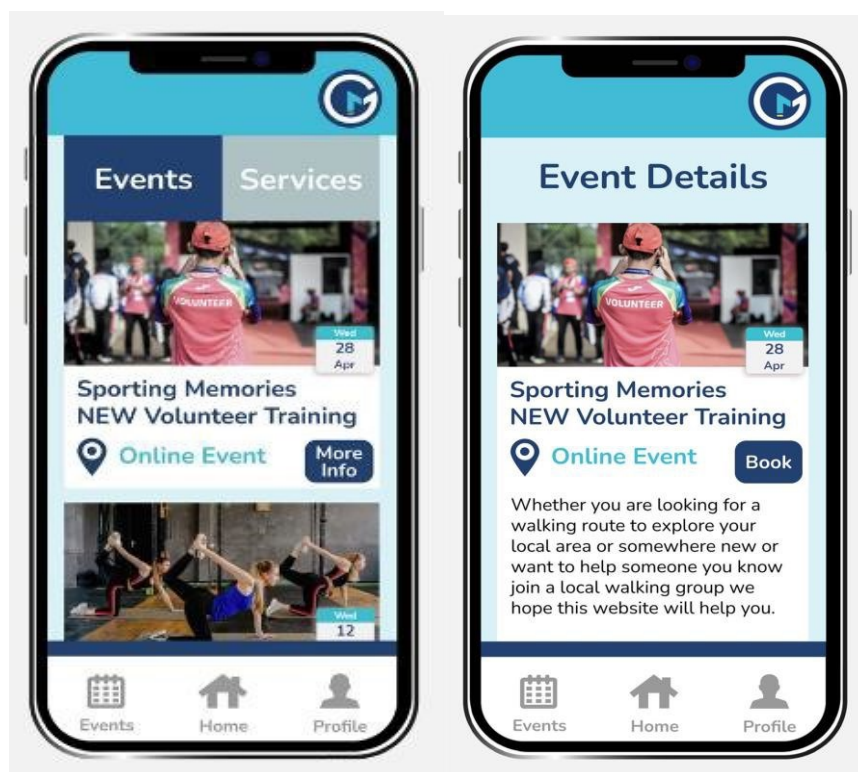
2. Scoring wellbeing



3. Recording a moment



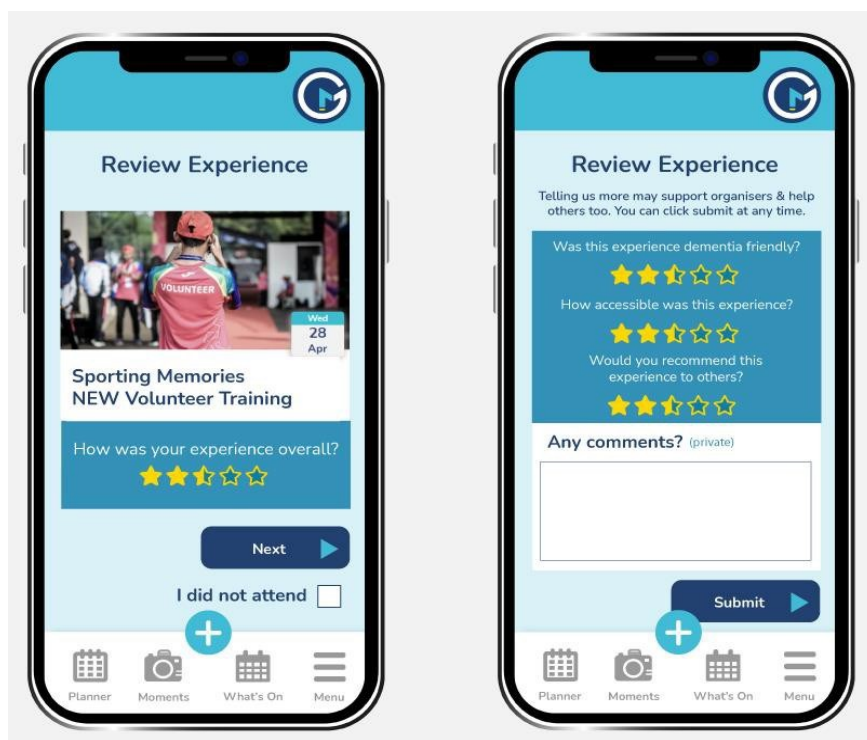
4. Accessing information on local events and services



5. Sharing events and news



6. Rating events



7. Personalised metrics





Department of Social Care and Social Work
Faculty of Health & Education
Manchester Metropolitan University
Brooks Building
53 Bonsall Street
Manchester
M15 6GX

For more information, please contact: d.tyson@mmu.ac.uk
Website: www.mmu.ac.uk
Twitter: [@MMUHPSC](https://twitter.com/MMUHPSC)