Sus-IT
Toolkit

Sus-IT
Keeping silver surfers on
the crest of a wave

A toolkit for engaging older people in research, design and development of ICT based products and services.

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Sus-IT: Sustaining IT use by older people to promote autonomy and independence
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A Toolkit for engaging older people in research, design and development of ICT based products and services

Contents

Preface

The **New Dynamics of Ageing (NDA)** Programme is an eight year multidisciplinary research initiative with the ultimate aim of improving quality of life of older people. The programme is a unique collaboration between five UK Research Councils - ESRC, EPSRC, BBSRC, MRC and AHRC - and is the largest and most ambitious research programme on ageing ever mounted in the UK (http://www.newdynamics.group.shef.ac.uk/).

The programme aims to develop practical policy, implementation guidance and novel scientific, technological and design responses to help older people enjoy better quality lives as they age. This requires integrating understandings of the changing meanings, representations and experiences of ageing and the key factors shaping them (including behavioural, biological, clinical, cultural, historical, social, economic and technological), through direct engagement with older people and user organisations. The programme will harness inputs from a wide range of disciplines to reveal the dynamic interplay between ageing individuals and their changing technological, cultural, social and physical environments - local, national and global - and to develop methods and means for overcoming the consequent constraints on the quality of life of older people.

This 'Toolkit' is an output from a project funded under the NDA programme: Sustaining IT use by older people to promote autonomy and independence (Sus-IT), a 39 month Collaborative Research Project (CRP) led by Leela Damodaran and Wendy Olphert. Grant No. RES-353-25-0008.

The Sus-IT project has explored the relationship between ageing and use of information and communication technologies (ICTs). ICTs have the potential to support older people to live independently, promote social inclusion and facilitate access to commercial or government services. However, as some people age they experience decline in their abilities, making it difficult to continue use of digital tools and services. The resulting disengagement from the digital world poses a significant threat to quality of life for some older people. A central objective of the Sus-IT project is to develop new knowledge which will inform design, policy and practice to mitigate the risks of digital disengagement and to generate design solutions.

Key research users (e.g. organisations representing older people and those providing services and products to be used by older people) have collaborated in the research. The project has been guided by an Advisory Group and supported by a number of external consultants. The Sus-IT project team includes partners from the following eight universities in the UK:

- Loughborough University (leader)
- Nottingham Trent University
- University of Lincoln
- University of Dundee
- Middlesex University
- Anglia Ruskin University
- University of Surrey
- Northumbria University

The team worked collaboratively with key stakeholder groups including user organisations and older people who participated directly in the project.

An underpinning principle in the philosophy of the NDA is the engagement of older people as active participants in research – in contrast to being passive research 'subjects'. In the Sus-IT project older people have been a core part of our research community. More than 1000 people from diverse backgrounds across the UK have participated in the project in some way. To engage and empower them, and thus build capacity in this community, a number of existing tools and methods have been tailored to the characteristics and interests of older people and used to engage successfully and effectively with them as research participants. Some of these tools and methods are particularly relevant to technologists/researchers from computer science and engineering backgrounds seeking to involve older people in their research, design and development activities. Prompted by the interest shown in these methods, for example, by conference attendees in response to presentations of Sus-IT research, and encouraged by a business consultant to the NDA programme and by members of the project Advisory Group, the authors compiled this document as a 'Toolkit' to facilitate engagement with older people.

1. Introduction

This Toolkit addresses the widespread interest and increasingly recognised need to engage older people in design and decision-making. The contents of this document are based on the work and experience of the researchers on the Sus-IT project which is described briefly in the Preface. It has been compiled by the authors primarily to support researchers, developers, designers, and practitioners seeking to engage older people in research, design and development. It has particular relevance for the design of technologies as a way of improving their match to the functionality and usability that older people want. For example through participating in imaginative co-design workshops or 'sandpits' with older people, designers and technology providers find they are better able to hear users' ideas (the tools and methods used in this process are elaborated in section 3.2.1 below). However, much of the content of the Toolkit has elicited interest from policy makers and practitioners as well as from designers.

The participatory approach which characterises the work of Sus-IT has been informed by the developing body of knowledge on the dynamics of ageing and new technologies and on effective approaches to user engagement in research/design/consultation processes. The processes and methods described and documented in this Toolkit have been developed and used with the dual purpose of promoting engagement *with* – as well as collecting data *from* – older people. They have the following characteristics in common:

- Tailored to needs and characteristics of older people
- Ethical and sensitive to diverse needs
- Aimed at building confidence and capacity of older people to contribute to research and design
- Designed to build capacity for multidisciplinary and participatory working

Thus this Toolkit comprises ethical and practical guidance and suggestions for tools and techniques to work collaboratively and participatively with older people to design and develop ICT-based products and services.

In the next sections, the rationale for user involvement is revisited and the components of the Toolkit explained.

1.1 Why involve older people in research, design and development?

The following extracts illustrate some of the current thinking on this issue from different perspectives:

" Designers should be encouraged to interact with older people and, if possible, to have older people as an integral part of the design process, because of their unfamiliarity and potential fear of computers. However, some older people's confidence in their ability to use Information technology can be fragile, and usability experimentation should not be put this at risk. Also, age related changes can exacerbate the problems inherent in conducting any focus group studies, with age related hearing loss being particularly problematic (Barrett and Kirk, 2000). Keats and Clarkson (2003) commented "that there are relatively few examples or guidelines for successful involvement (of older and disabled people), and often traditional formats have to be adapted". Hypponen (1999) states that "there were many different methods of choosing how to collect user needs and integrate them into product development, and that the suitability of this approach (user centred design) to accommodate a range of disabilities into the design process (in an effective and efficient manner) is unclear".

Newell, A. Morgan, M. Gibson, L. and Forbes, P. 2011. Experiences with Professional Theatre for Awareness Raising. Interacting with Computers, Volume 23, Issue 6, November 2011, pp.594 – 603

There are two main reasons why older people should be involved in ageing research. First of all, as a matter of human rights, like any human research subjects, older people have a right to be consulted about research that is being conducted on them. Arguably this imperative is particularly strong with regard to older people because of their experiences of age discrimination and other forms of social exclusion. The only question, therefore, should be how much consultation/involvement? The answers will differ between and among disciplines. Access to the meaning of old age, however, cannot legitimately be attempted scientifically without the active engagement of older people as participants of various kinds in the research process rather than 'objects'. Needless to say the results of research conducted within this participative framework will be enriched by a dialogue based on older people's interpretations of their own lives and experiences and the researcher's. Secondly, if researchers want to produce findings that might contribute to the quality of life of older people or the quality of the services or products they use, then it is essential to involve them so that they can contribute their own understandings about ageing and service use which can often be far removed from those of scientists and service professionals (McKevitt , Baldock , and Hadlow, 2005). The well documented partial and precarious take-up of assistive technologies (McKevitt , Baldock , and Hadlow, 2005; Digital Inclusion Panel, 2004) is just one example of the inadequacy of attempts to involve older people in identifying needs and appropriate solutions (Cowan and Turner-Smith, 1999).

Walker, A. Why involve older people in research? Age and ageing, volume 36, issue 5, pp.481 – 483. 2007.

"Inclusive design is a term that has been defined as ensuring that "products and services address the needs of the widest possible audience, irrespective of age or ability" (Design Council, 2003). Advocates of the movement argue that "getting things right for older users leads to real improvements in usability and customer satisfaction, which translate into better products for people of all ages" (Coleman, 2001, 37) This is an important design movement which has resulted in many innovative approaches to new and old technology. But a broader conceptualisation of the term "inclusive" might take into account not just different physical abilities but different socio economic power. Older people are excluded from technology not only by physical disability. Over 75 year olds are far more likely to suffer financial hardship than other age groups and may be excluded from technology simply because they cannot afford it. Changing notions of community must be recognised as design challenges for systems that aim to support the ageing population. In short the aim of those that seek to make technologies that will meet the challenges of the ageing society must strive not just for mechanical and functional dependability but also for social dependability".

Blythe M, 2003. Net Neighbours: Dependability, Accessibility and Online Shopping for Older People. HCI 2003 workshop "Designing for Civil Society".

" The participation of older people in all stages of the design process, including decision making regarding the design, installation and use of digital assistive technologies has wide-ranging benefits. The main benefits of their participation are summarised below:

1. *Better understanding of older people's changing needs. These may include their hopes, fears, aspirations and problems.*
2. *Learning and capacity building. The development of knowledge-sharing mechanisms can benefit both the designers of digital assistive technologies (who become aware of older people's needs) and the beneficiaries of these technologies (who become informed about the opportunities provided by new technology and how these opportunities can improve the quality of life). In the latter case, beneficiaries (i.e. older people) can build capacity which will enable them to contribute to the design process. Furthermore, new knowledge can be created and deposited in knowledge management systems for future learning.*
3. *Faster technology diffusion. The design of more user-centred and relevant digital assistive technologies can speed up their adoption/uptake by older people.*
4. *Sustainability. The engagement of older people in the design process empowers older people, giving feelings of ownership and control over digital assistive technology. These feelings are important motives for continuous involvement in the planning, development, implementation and maintenance of technology. As a result technology continues to serve older people's needs."*

Olphert, C.W, Damodaran, L., Balatsoukas, P., Parkinson, C. 2009. Process requirements for building sustainable digital assistive technology for older people. Journal of Assistive Technologies, vol 3, Issue 3, September 2009, pp.4-13.

Thus the value of engaging older people in design can be summed up as follows:

- It builds confidence and capacity in older users in using and adapting technology to meet their own needs;
- It develops technical skills and understanding of their own needs and how they are changing;
- It aids in the elicitation of rich user requirements of ICT products, systems and services - reflecting context, needs, hopes and aspirations;
- It promotes uptake and adoption of technologies by older people.

1.2 Approach and contents of the Toolkit

This Toolkit comprises three components:

(i) Guidance on process and procedures for managing the engagement process – including an overarching Research Ethical Governance Framework and guidance on engaging older people in testing and evaluating software/hardware.

(ii) Tools and Methods

- o Questionnaire-based surveys (including use of pictorial questionnaires)
- o Story-telling techniques
- o Interactive forum theatre
- o Co-design workshops (sandpits)
- o Participatory problem-solving workshops

(iii) Further reading/ source material: this section of the Toolkit indicates some sources for further exploration of the issues raised in this document.

In addition, for more details of the Sus-IT project, see Annex 1: 'Sus-IT project Overview' and Annex 2: 'Engaging older people in research and design'. Annex 3 provides a full list of Sus-IT project publications. This list includes publications that describe in more detail some of the tools and techniques and the issues involved in working with older people which arose in the course of research on the Sus-IT project.

All briefing papers on the Sus-IT project are also available online at: http://sus-it.lboro.ac.uk/SusITBriefingDocs.pdf

2. Managing engagement: guidance on process and procedures

2.1. The rationale for a research ethical governance framework

It is mandatory for all those conducting research and development activities with older people to comply with the requirements of the relevant ethical framework in place at their institution. Most institutions have their own ethical frameworks, and procedures and codes of conduct have been generated by Learned Societies and professional bodies, by Research Councils, and by Ethical Committees in universities and in the NHS and so on. This being the case, any engagement process undertaken with older people in the context of research and development whether in an HEI, a hospital, a commercial organisation or any other context will be bound by requirements for ethical practice. ***So why the need for this research ethical governance framework?*** There are several compelling reasons for producing this framework*.* One reason is that existing frameworks and approval procedures differ from each other in various ways – e.g. in the definition of vulnerability and there is a need for a consistent approach across a collaborative project. They also have in common a legalistic and often mechanistic approach in which avoidance of harm tends to be the predominant shared and overriding concern. Avoidance of harm is of course a crucial and essential requirement to safeguard all participants in research. It is however not sufficient to ensure that the well-being, self-respect and interests of older participants in research are adequately considered and safeguarded. Reports from organisations representing older people and from some accounts and observations of academic practice suggest that there is poor practice in the field. Although it is likely to be the case that these deficiencies do not cause actual physical harm, they can nevertheless cause unease or distress for research participants. It appears to be the case that as more and more research is conducted with older people, shortcomings in practice are becoming more evident and this can lead to older people being reluctant to participate in research. These realities have led to the recognition of a significant gap in guidance available on engagement practice with such participants. The development of a Research Ethical Guidance Framework (REGF) was therefore driven by a concern to promote good practice and to make the process of research participation a positive, enriching, rewarding and satisfying experience in which lived experience and resilience are respected, the diverse contributions of the older person are valued, and appreciation of their participation is reflected in the nurturing and caring approach taken to their well-being at all stages of the research process.

Most of the shortcomings identified can be addressed by changes in approach and 'mindset' and by small changes in practice. Some of the deficiencies which occur include failure to provide basic information, for example, regarding the existence of a security barrier at the entrance of the venue and associated guidance on what to do on arrival, how to explain why you are there, where to go and for whom you are looking etc. These deficiencies can make the process of engagement in research, design or consultations uncomfortable for people - especially those who might be feeling vulnerable, anxious and perhaps lacking in confidence - and tend to create reluctance to engage in research in the future. In the engagement process itself, such unease may mean participants do not ask questions because they fear they will 'look stupid' to the academics and researchers present (who sometimes outnumber the research participants); assuming familiarity or prior knowledge of the research - and therefore not giving adequate explanation in layman's language and thus leaving the person feeling unable to really engage with the process. To address what cumulatively amounts to a serious deficiency and a significant gap in standard ethical procedures, this REGF has been developed by researchers on the Sus-IT project, informed by their wide-ranging experience working with older participants and through collaboration with members of the Advisory Group of the project.

2.2. Role and function of the REGF

It will be evident from the discussion above that the primary objectives of developing the REGF are two-fold:

1. To ensure a level of consistency in ethical practices across institutions involved in research as part of a collaborative process.

2. To ensure that participants have a rewarding experience whilst undertaking research.

The REGF is a set of guidelines to promote best practice in working with older people. The content is based on expertise of the collaborating partners in Sus-IT in working with older research participants. Thus the guidelines incorporate practical experience of research involving older people over a number of years, and reflect published best practice, e.g. Dickinson, Arnott and Prior (2007).

The REGF also expands on the ESRC Framework for Research Ethics which specifies the following six key principles of ethical research that should be addressed in ESRC-funded projects, whenever applicable:
- o Research should be designed, reviewed and undertaken to ensure integrity and quality.
- o Research staff and subjects must be informed fully about the purpose, methods and intended possible uses of the research, what their participation in the research entails and what risks, if any, are involved. Some variation is allowed in very specific and exceptional research contexts for which detailed guidance is provided in the policy guidelines.
- o The confidentiality of information supplied by research subjects and the anonymity of respondents must be respected.
- o Research participants must participate in a voluntary way, free from any coercion.
- o Harm to research participants must be avoided.
- o The independence of research must be clear, and any conflicts of interest or partiality must be explicit.

(Adapted from: Dickinson, A., Arnott, J.L. and Prior, S. 2007. ESRC Framework for Research Ethics).

It is important to note that the REGF has been developed to complement existing ethical frameworks and procedures and is emphatically not intended as a replacement for them. All partners in a research project will be required to comply with the ethical approval procedures and processes of their host institution. Variations in processes from institution to institution are common. In a research collaboration involving more than one institution, the ethical regime to be followed for any specific research task will be that of the institution to which the individual responsible for the conduct of the task is affiliated.

2.3 Approaching, recruiting and briefing research participants

2.3.1 Approaching and recruiting participants

When approaching and recruiting participants, take account of the following considerations:

a) Recruiting

- Ensure that participation is completely voluntary, without any pressure being exerted by researchers (or others) on individuals to participate.

- Where people are recruited from an existing group such as a computer club, emphasise that if they choose not to participate in a research project, their membership of the group and participation in its activities will not be affected in any way.

- Ensure that recruits are selected carefully. In particular, pay due regard to any inclusion or exclusion criteria identified for involvement, before the participant arrives to take part. It is not good practice to have people arrive at a venue expecting to participate in a research task only to learn that they are unsuitable (e.g. on account of a visual impairment); such an experience can be embarrassing, cause feelings of rejection and create annoyance over wasted time and effort. To avoid such negative experiences, pre-screening (e.g. by telephone interview) should be a standard part of the participant recruitment process.

- The number of participants to be recruited will depend on many factors, such as the nature of the activity, the need for representativeness of different characteristics and the timescale and resources available from researchers. Appropriate guidance is available in research methods textbooks. As a general guide for group based activities, (e.g. focus groups, sandpits etc.) between 6-10 participants is an appropriate number. Some tasks will require one to one interviews, and for others larger groups/workshops will be appropriate. In the case of large group events it is often useful to divide the participants into smaller groups for discussion and deliberation of specific topics, since not everyone is confident speaking in a large group.

b) Accessing gatekeepers and approaching individuals

- Send an introductory letter or email with specific details of the project and details of what will be required of participants when approaching individuals or gatekeepers (i.e. individuals within an organisation who are the main point of contact). Provide the name and contact details of an individual who can answer any questions or concerns clearly and without ambiguity. Offer appropriate reassurances about the safeguards in place regarding use of any personal details provided.

c) Inviting individuals to participate

- Send a clear and simple letter to potential volunteers to invite them to a briefing session at your host institution or at a suitable and accessible venue nearer to where the volunteers live. If volunteers have to travel to the venue then the nature of any assistance with costs of travel and other expenses should be made clear. Volunteers with reduced mobility may need additional assistance in both travel and at the briefing venue.

d) Knowing about specific disabilities

- The selected participants may suffer from problems with dexterity, vision or some other physical impairment. Use of a **pre-study screening questionnaire** may be advisable to help identify issues which may prevent participants from completing the research successfully. This also provides an opportunity to develop solutions to overcome the problem or to make arrangements for appropriate additional support.

2.3.2 Briefing research participants

a) Explaining the project

- Provide details about the research and the process involved in conducting it. Include information on the why the research is needed, the anticipated potential benefits of the project (illustrated by practical examples relevant to the needs or interests of the research participants in particular and to other older people more generally), the likely time horizon before results will be available to inform changes in design/policy/practice and so on. It is important to convey this information in a clear and concise verbal presentation and to support this with an information pack provided for each participant.

The pack should include key documents such as a project information sheet and participant consent form (these two documents are statutory requirements in most, if not all, recognised research ethical frameworks).

- Further information such as pamphlets about the project may also be of interest to participants but avoid overloading them with non-essential documentation.

b) Explain the research task

- Provide verbal and written instructions with specific and detailed information about your research and the research task in which the individual will be engaged.

Depending on the ethnic diversity of the participants, translations of the above information (and in some circumstances the services of a suitably trained translator) may be required.

2.3.3 Ethical aspects

To ensure that you have participants' informed consent, in addition to covering the points above, provide BOTH oral AND written details of:

a) Issues of anonymity, privacy and confidentiality

- It is important to state details of the Data Protection Act and to confirm that no personal data (e.g. names, addresses and contact details) will be shared with third parties. Also be clear about who will have access to the data, where the data will be stored, what will happen to the data after the project has finished, what you will do to preserve anonymity, and how the data will be used.
- If there are, or could be, issues related to protecting the IP that might arise from the participant interaction, it will be important to ask participants to sign a confidentiality form to protect patentability.

b) Consent issues

- Be clear and ensure that participants understand that their participation is entirely voluntary. Make clear that they are able to withdraw from the study, refuse to answer particular questions or not take part in a particular part of the testing, at any time and without providing an explanation. It is also important to outline that participants can choose to withdraw their consent after the data collection activity has ended (if there is a limited time frame for this then advise participants appropriately).

2.3.4 Research methods

While research methods will be selected on the basis of their suitability for addressing the underlying research questions, be aware of potential shortcomings certain methods may have in the collection of data from some older participants. For example, self-reporting methods, such as diary studies, may be less successful in gathering useful data due to some older participants' reduced short-term memory span, limited literacy, or perceptions of what data they feel should be recorded. 'Think-aloud' methods, which encourage participants to voice their thoughts as they concurrently attempt a task (often using ICT), may be less successful for older participants due to the cognitive demand of interpreting and describing what they see, think and feel.

Be aware also of the tendency for some older participants to 'want to please'. This means they may react overly positively when describing or rating technology they are asked to use (which may be in contrast to observed difficulties they have had in using it). When participants know, or think, that the technology being tested has been developed by the researchers present, particular care should be taken to assure them that it is their genuine opinions/evaluations that

are sought – and that they should not hold back on account of their concerns to avoid giving offence/causing upset.

2.3.5 Timings

Be as flexible as possible, and err on the side of over-estimating the time likely to be taken in carrying out the research task – while at the same time minimising the time commitment required by participants.

Older people tend to take longer to complete tasks and like to read instructions slowly and carefully before starting a study, so ensure that there is sufficient time for this. It is important to avoid making the research participants flustered, which can happen if they feel rushed. Older people may also welcome the opportunity to talk to researchers more generally for example about the nature of the research and its wider applications and potential value. It is very important to schedule adequate time for this knowledge exchange and participation.

Be aware of the impact of bad weather on scheduling of research activity. Older participants may be particularly vulnerable when making journeys in adverse weather, yet may feel obliged to attend despite the hazards and their concerns. Be prepared to offer participants the opportunity to reschedule research activities in periods of bad weather.

2.3.6 Accommodating participants

a) Providing information

- Where the participant is new to the research project, give them clear and concise instructions to enable them to easily find the correct location of the research activity, and advice on what they should bring (e.g. reading glasses).

- Provide reliable contact numbers for research co-ordinators, so they can be reached easily by the research participants.

b) Reminding participants

- Consider contacting the participant the day before the event, e.g. by phone, to remind them of their appointment details and to check that they are clear about what will be involved and have no misconceptions of details provided to them.

    Memory problems are common and a gentle reminder about the event can reduce the likelihood of people forgetting to attend on the day.

c) Environmental factors

- Try to use ground floor space as close to the building entrance as possible, particularly if recruiting frail elderly people with mobility problems who may find stairs a particular problem.

- Ensure where possible someone is at the building entrance in plenty of time to meet and greet participants, particularly those with mobility problems, to escort them to the research area and provide any assistance required. Note that older people may be more likely to be punctual, or early, in comparison to younger participants!

d) Opportunities for social interaction

- It is important to provide participants with opportunities for social interaction. Where a number of participants are involved in a group study, consider inviting them to arrive half an hour early to allow them time to meet and socialise with the other participants.

- Opportunities for social interaction can be a very important part of the research engagement process for older people who may have reduced opportunities for meeting

people. Arranging to have for a suitable space for this to happen is sometimes a challenge but it does work well and usually means that participants are less reticent about speaking in a group situation as they have likely to have broken the ice before the research activity begins. The provision of refreshments such as tea and biscuits is usually welcomed enthusiastically! When providing meals or refreshments it is good practice to make provision for diverse dietary needs and preferences of participants.

e) Accommodating companions

- Be aware that is not uncommon for people to want to bring a companion with them, and consider whether it will be appropriate for a companion to be present in the research activity.

- In situations where it is not appropriate for a companion to be present during the research activity, make this clear and ensure the companion is provided with appropriate hospitality (e.g. a comfortable room in which to sit with magazines and refreshments) while the research activity takes place.

2.3.7 Invite and encourage questions before proceeding

Allow plenty of time to cover the issues above in detail, and before proceeding, to ask participants to sign the consent form. Always **allow ample time for questions**. It is important to address any issues as they arise and to check that your response has been dealt with to the satisfaction of the person who raised query.

2.3.8 Privacy

a) Right to access data

- Ensure that participants are informed that they have the right to access any data given as part of the research project. In addition it is recommended that access to data should be restricted to the project team. If results are to be used in publications then it is essential to anonymise the source of the data so that identification of individuals is not possible.

b) Data security

- When taking details such as phone number and address, always reassure participants that this information will not be passed on to anyone without the participant's prior permission.

- Institutions will have their own stipulations for storage of and access to research data; at a minimum, keep data in a double locked area, and ensure that it is accessed only by authorised people.

2.3.9 Printed documentation

Ensure printed documentation such as consent forms, information sheets and experimental instructions are designed to ensure readability and comprehension, by following best practice in inclusive print design. Again, depending on the ethnic diversity of participants, consider the need to provide documentation in alternative languages.

Examples of good practice are as follows:

- Use at least 14 point font size, left-justified text.

- Use graphics where appropriate to aid comprehension.

- Language should be straightforward, 'everyday' English, with particular effort taken to avoid unnecessary or inappropriate use of technology-related jargon.

- Avoid ambiguous instructions or statements.

- Instructions should be tested prior to use

Older adults may have sensory and cognitive impairments that affect their ability to read printed content. A sample of older people is likely to have a particularly wide variety in literacy and education levels, with a significant proportion having relatively poor literacy. Print literacy can take a number of forms due to eyesight, cognition and poor education or English as a foreign language. For this age group, factors contributing to literacy levels include early school leaving age (12-15), education interrupted by World War 2 (WW2), cases of undiagnosed dyslexia, the impact of immigration as well as any deterioration as a consequence of ageing. It is important to note that reading glasses or special prescriptions for use with computer screens may be an additional cost barrier for some older participants.

This means that great care and tact is needed to see if a participant appears to be having difficulty reading a document – or shows reluctance to pick up written material – and to offer discreet help if appropriate. Clear verbal briefings should in any case be given –and it is important to talk through all documents and to offer unobtrusive help e.g. to complete questionnaires/forms on their behalf – safeguarding their privacy by moving away from other people to work with them in a quiet spot.

2.3.10 Participation management during and after the research activity

a) Right to refuse or withdraw

- Participants have the right to refuse to answer any specific questions during the research, without having to explain why. Ensure this entitlement is made clear to them - verbally by the researchers and in written documentation.

- Participants are always entitled to withdraw from any research activity at any time without penalty. Ensure this entitlement is made clear to them - verbally by the researchers and in written documentation.

b) Debriefing

- Ensure that wherever possible, at the end of the research activity, participants are debriefed on the purpose of the research. The debrief process should include asking the participant again whether they are giving consent for their data to be used in research analysis.

2.3.11. Dealing with issues emerging from the research activity

a) Vulnerable participants

- Institutional variations exist on whether older people are categorised as 'vulnerable' participants; so each partner should be certain of their own institutional definitions and processes and the implications of working with 'vulnerable' people.

b) Complaints

- Ensure there is a procedure in place to deal with complaints from participants, or situations where participants report discomfort or distress during, or after, the research activity, and that this procedure is followed whenever such feedback arises.

- o This may involve dealing with situations where a participant blames a subsequent health issue on the research activity, and may require gentle reassurance that the research activity was not responsible for the problem they describe.
- o Regardless of the cause of the reported problem, it is important to treat participants with due care and respect. This will also minimise the chances that they refuse to participate in further research activity.

c) Clinical data

- Any activity that is expected to gather clinically sensitive data will be governed by NHS ethical approval procedures, and researchers must follow these at all times.

- In some cases, it is possible that the research activity may potentially generate data that has clinical implications, for example possible evidence of depression. In such cases researchers should:
  - o Inform the participant as sensitively as possible that data exceeded expected values
  - o Recommend that they discuss this with their GP as they may benefit from doing so
  - o Provide the participant with a print-out of the study summary, why it used this measure, which specific measure, their score, the researcher's recommendation that they seek advice, and contact details for a GP to use to contact the researcher if required
  - o Withdraw the participant from the study at this point.

2.3.12 Contact arrangements during longitudinal studies

In the case of longitudinal studies you may need to contact participants periodically to ask them to carry out specific tasks. If so, indicate how frequently you will be in contact, how (i.e. email, letter, phone) and provide details of the types of tasks they may be asked to carry out. It is important to talk to participants about their availability before data collection begins, to ensure that it is convenient for them and will not be imposing on their caring/work/other commitments.

2.3.13 Share findings/outcomes

One of the most common complaints from older people who participate in research studies is that they are rarely given the opportunity to find out how their contributions informed the findings and outcomes of the project. Many older people value the opportunity to find out how their participation helped the research process and beyond. Thus it is important to provide an opportunity for a post-data collection follow up event to share findings and forward plans – and to thank participants. Inviting them to attend end of project demonstrations or showcase events promotes capacity-building and goodwill regarding participation in research.

2.4 Guidance on engaging older people in software/hardware testing: achieving a rewarding participant experience

To comply with the ethical approval requirements of your institution you will of course need to provide the standard components which will include details on sample characteristics, approach/access to gatekeepers/individuals; methods to be used; details of how anonymity, privacy and confidentiality will be safe-guarded; sample documentation: e.g. interview schedules; letters of invitation; participant information packs which includes details of the project, research task, information sheet detailing issues of anonymity, privacy and confidentiality etc.

In addition to meeting these mandatory requirements, in order to help participants achieve a rewarding experience in any software or hardware evaluation you are conducting, it is recommended that you adhere to the following guidelines:

2.4.1 Explain the benefits for participants

Clearly explain the potential intrinsic value for participants and the intended benefits of the work in helping older people more widely. Participants would benefit from knowing how their participation can be used to improve future iterations of hardware and software, identifying and addressing any issues that arise with common usage, how software can be re-designed in light of comments provided as well as how the results of the research will be disseminated to designers (and if so, how and when?). It will be important to answer these questions in the context of the aims and objectives of your own research project so participants are clear how their contributions will be used.

2.4.2 Clarify data collection

Be clear about the type of information that will be collected. For example, in the case of testing software which is to be installed on participants' own laptops, re-assure participants that you will not have access to files on their computer, details of websites etc. they visit, or any other personal details that may be stored on their computers. It may also be useful to show examples of the data to be collected e.g. a demonstration of what a 'log file' looks like. It is important to ensure that all participants are comfortable with the information you have provided, are clear about the task they are to carry out and do not have any fears, worries or concerns before proceeding to sign the consent form.

- Reassure participants that it is the technology that is being tested, not them, and it is their thoughts and comments about ease of use of functions etc. which will help improve the design or functionality of the software or hardware.

- Be prepared to spend some time ensuring that the point above has been clearly understood, and be aware of situations where the participant may not have fully appreciated this. Reiterate the point if necessary, perhaps re-phrasing it to help comprehension. Many older people have had negative past experiences of school tests, where it was not uncommon for the teacher to tell pupils that they were stupid or even to administer corporal punishment for performance considered to fall short of required standards.

- Always explain that if participants encounter difficulties when using a system, it is because the system may not have been designed with the needs of its users in mind, and that the researchers are particularly interested in finding out what participants find difficult, in order to establish how the system can be improved. This helps to relieve any negative feelings loss of self-esteem and such feelings of inadequacy that participants may experience whilst participating in the research.

- Where the system being tested is a prototype, make this clear to participants at a suitable time during the research activity, so that they are aware that the system as it stands is designed for research and development purposes and for testing (rather than being close to launch as a mature product – i.e. they will not be able to buy the device in the shops, at least not for some considerable time).

2.4.3. Provide on-going support and contact

Although it may be technically impossible for the software/hardware being tested to cause any unintended interference with the user's computer system, it is crucial to recognise that if any problem should arise following any trial or experiment, there is a high likelihood that the coincidence will be assumed by a non-technical participant to be causal. It is therefore critically important to provide adequate explanation, reassurance and support throughout the duration of the study. Reassure participants that the software/hardware has been tested rigorously to ensure that it will work as intended without causing any problems. It is also important to re-assure participants that if they do have any concerns, they are able speak to/contact you with ease (make sure arrangements are in place to ensure this is feasible and reliable). Also be sure to advise on the waiting time for a response from you if they are not able to get hold of you immediately. At this point, it is also worthwhile to remind them that they are able to withdraw from the study at any stage.

2.4.4 Demonstrate the new technology

It is important to demonstrate the hardware/software so that it is not entirely unfamiliar to participants when they use it for the first time. It may be the case that because of your research design it is not appropriate to show the full functionality of the software/hardware. If this applies, it may be useful to develop example scenarios of when/how the software/hardware can be used. If you do use example scenarios, make clear to participants that you are providing an illustration rather than a demonstration of what they will be testing.

2.5 Application

The Research Ethical Governance Framework (REGF) is based on the work, experience and contributions of researchers working with older people over a number of years and has been greatly influenced by the important pioneering work of colleagues from the School of Computing at the University of Dundee on the Utopia project. The document has been compiled by the authors primarily to support researchers, developers, designers, and practitioners seeking to engage older people ethically and effectively in research, design and development. It provides guidance on how to actively safeguard and promote the well-being and peace of mind of participants and provide a rewarding and enjoyable experience for them.

The document also offers guidance and practical suggestions for how to work collaboratively and participatively with older people to ensure that they are actively engaged, at ease and comfortable in the research process.

The REGF is not designed as a replacement for existing ethical frameworks in use in HE and other research environments but as a complement to them. The content is intended to fill a significant gap in most existing procedures by taking account of the needs and characteristics of older research participants in the detailed planning, preparation and administration of the research task. Guidance is provided on the relevant issues to consider and ways to promote the well-being during the research process such that the participants experience their research role and activities as rewarding and worthwhile.

The expectation is that the REGF will be used sensitively and flexibly to suit the circumstances of the participants and the requirements of the research design in conjunction with existing ethical codes and frameworks already in place.

The Research Ethical Governance Framework was circulated for comment to relevant stakeholders including researchers, user groups and members of the SUS-IT advisory group and their feedback has been incorporated.

3. Tools and methods

This section describes a number of different tools and methods used on the Sus-IT project to develop knowledge and understanding of ICT use by older people. They have been used, variously, to gain awareness, insights and understanding of older ICT users' experiences, to inform practice, policy and design and to facilitate co-design and user-led design and decision-making. Older people are far from being a homogenous group (Gregor *et al.* 2002) and show considerable diversity in their capabilities, well-being and experiences. Gregor *et al.* (2002) challenged researchers and developers who are working with older people to seek out diversity and to employ a design process that is sensitive to this diversity. The research and design methods described below attempt to reflect and incorporate that philosophy and approach. While none of the tools/methods described in this Toolkit is in itself novel, each has been used in innovative ways or in combinations which take account of the life experiences, characteristics and needs of the older people involved in the research.

3.1 Understanding the experience and requirements of older users

3.1.1 Questionnaire surveys

Survey methods offer a useful way of collecting data. As these are widely used and well documented elsewhere in numerous papers and textbooks (e.g. Cohen, 2007), comments here are restricted to a generic few points relevant to working with older people. The design of the survey tool should be tailored for use with older people (e.g. ensuring the text is size 14 font etc.) and the way in which the survey is administered also needs to be carefully adjusted to take account of the needs and characteristics of older people. For example, administering the survey in a group setting (as opposed to postal surveys) allows the opportunity to provide participants with a carefully-paced briefing on the project and research task and also provides participants with an opportunity to ask questions about the research/task in hand as well as raise any consent issues. Additionally, with the support of a researcher on hand, participants are able to check their understanding of the questions and also talk informally about the topic under investigation.

For those with a low level of literacy, a pictorial questionnaire can be useful in data collection. It makes use of images as a basis for questions, instead of relying only on verbal questions. For example, it can be used to present images (e.g. of technological devices) for people to rank e.g. in order of preference, importance, frequency of use. It is good practice to have an assistant to help the respondent in order to prevent misinterpretation. As an example, in the Sus-IT project, a shortened version of a Digital Engagement survey tool was produced, (one side of A4 paper in 14 sized font), with pictures and taking just a few minutes to complete (Keith, 2010).

3.1.2 Storytelling techniques

The use of storytelling is well-established as a data collection technique to elicit from research participants a narrative of their experiences of the subject/issues being researched. It provides an effective way for people to explain their experiences from their own perspective, using their own words and concepts. The technique therefore offers a way of overcoming the limitations of tools such as questionnaires, which provide a restricted set of questions and standard vocabulary (Henn *et al.,* 2006) which may not encourage, indeed may inhibit, respondents in communicating their experiences. In contrast, stories can convey the participant's aspirations, hopes, fears and experiences in a way which is structured by the narrator's own perspective and context. This makes the technique particularly appropriate for investigating the use of technology by older people who often feel they know little about computers/the internet and can be reluctant to answer specific questions on a subject about which they lack confidence in their

own understanding or competence. Another significant advantage of storytelling especially for older people is that it includes people that otherwise would not be able to contribute due to a low level of literacy they might possess. In the Sus-IT project, storytelling was used successfully in a conversational and informal way to elicit accounts of the experiences of older people in using ICTs. In recalling their initial encounters with ICTs, participants were able to clearly articulate the drivers for digital engagement, their aspirations for ICT use and their hopes and fears in using ICTs (Hardill *et al.* 2010). The process also provided rich descriptions of ICT usage which included the joy of discovery as well as the overwhelming fear and frustration felt by some learners during problematic episodes in ICT use. These gave the researchers important insights and better understanding of older adults' ICT "learning journeys". Of particular value in developing a body of knowledge about older people and their use of ICTs are the longitudinal perspectives gained from following the unfolding stories of lived experience and development from pre-use to established use. Such information and knowledge can be used to inform and improve learning and support provision and to elicit user requirements for ICT product design. Thus the knowledge derived from the use of storytelling has provided a rich understanding of challenges older adults face both in learning to use and in sustaining use of ICTs which is informing design, practice and policy.

3.1.3 Interactive forum theatre (or DVD)

This method uses drama techniques to elicit user experiences and requirements through a combination of dramatic enactment of future scenarios and hands-on engagement with working demonstrations. Interactive theatre has been used in a wide range of training and therapeutic contexts to good effect, sometimes achieving transformational change for individuals and organisations. The particular benefit that this method offers for engaging older people in research, design and development is that it provides a compelling way of enabling them to learn about ICTs which they might not otherwise encounter and to explore the implications for their own lives of the potential for such technologies to prolong autonomy and independent living. Use of the method gives older people opportunities to explore aspects of current and emerging technologies in an entertaining and engaging format. The fact that older people are often enthusiastic theatre-goers, familiar with and comfortable in the theatre environment is conducive to their learning and participation in discussions of ICTs and related issues. This is important in combatting the natural reluctance older people often have in commenting on technology or making suggestions for improvements to it.

In addition to the value interactive forum theatre offers in engaging older people in issues relating to ICTs, drama is a powerful method of helping policy-makers, practitioners, Human Computer Interaction (HCI) designers and other stakeholders to gain *empathy* with older people. It does this by increasing their awareness of specific problems, emotional and attitudes of which they would not otherwise be cognisant. For example, even if ICT designers read stories of a user's experience, theatre helps them to engage with the experiences portrayed in such accounts in a much more compelling way so that they gain stronger identification with the users and are motivated and inspired to meet the real needs of users – in this case, older people.

To ensure that dramatized scenarios are accurate representations of real problems experienced by users, the script preparation has to be carefully planned, informed by research and developed in an iterative process where draft scripts are rehearsed by professional actors and evaluated and modified by users and researchers before a final dramatization is produced (Newell *et al.* 2011, p.4).

The drama can be shown as live theatre or, where a lower cost option is necessary, by use of DVDs instead. Live theatre is particularly effective because actors can respond to questions from the audience while they are still in character. At the end, the actors give up their roles and

participate (as themselves) in a discussion with the designers and users. This process allows designers and others in the audience to state their views and to ask questions freely without the fear of offending anyone. Newell *et al.* (2011) found that live theatre changes designer attitudes about the needs of older people. On the Sus-IT project, researchers used interactive theatre to good effect in a co-design workshop or 'sandpit' where it helped the older people participating in the workshop to envision the design possibilities for future technological devices and to assess the potential value and acceptability these might offer in their own lives (Frohlich *et al.*, 2010). A DVD which conveys some critical aspects of ICT use by older people has been developed through collaboration of Sus-IT researchers (Olphert *et al.*) with Maggie Morgan (MM Training) and David Goodall (Soundsmove Film Production) (Goodall, 2012).

3.2 Involving older users in the design, planning and policy influencing process.

The following are tools to encourage effective engagement of older people in design of technology and to elicit user requirements.

3.2.1 Co-design workshop (sandpits)

Sandpits are interactive sessions where older people can explore current and emerging technologies in a playful and creative context. A number of technology demonstrators are used to introduce the participants to technologies which will be unfamiliar to them. The sessions help to create awareness among older people of emerging technologies, and give ideas about how the ICTs can help to improve their lives. Sandpits also allow opportunities for the sharing of experiences and collaboration where older people can have a voice and role in specifying what they want from new and emerging ICTs. This process also has considerable potential to provide designers with new ideas and user-generated requirements for product design.

The innovative use of 'sandpits' on the Sus-IT project has had an important impact on engaging older people in the design process and on the design community. The evidence shows that with appropriate and stimulating methods of engagement older people were comfortable and creative in the sandpit environment and had much to contribute to shaping design concepts and technology developments. Older people who participated in Sus-IT sandpits reported that they were surprised at their own creativity and felt empowered by their contribution to design decisions.

Using sandpits to promote creative product design requires clear presentation of open-ended product concepts for re-design. In one example of the several sandpits conducted on the Sus-IT project, design concepts were presented to two groups of older people – in one group, the participants assigned to it were all 'digitally engaged' (i.e. regular users of own PC at least three times a week or more) and in the other group they were 'digitally unengaged' (i.e. did not own or use a PC). In the first exercise, each group of participants took part in discussion of the concepts and feedback was elicited from them in a focus group setting. They were then split up into smaller groups and encouraged to consider what aspects of the design they would wish to '*keep'*, *'lose'* or *'change'* in the design of the eventual product. Each group was facilitated by a designer/researcher who created sketches to reflect and illustrate the ideas for the new product forms as they emerged and were being discussed. The facilitators were able to use their design expertise and knowledge of production processes to ensure that feasible and viable product concepts were generated by the co-design/ sandpit process. This approach of starting with a variety of different artefacts and then engaging participants iteratively in the proactive process of deciding to keep/lose/change features appears to be a successful way of eliciting good-quality feedback and of empowering people (who may not have been able to imagine the possibilities before the sandpit) to generate design ideas. Examples of innovative re-designs of concepts which were generated by older people in the sandpits include the portable "myStory" device and

the "iTutor" iPad app which are described in Frohlich *et al.* (2010). A number of the concepts which were generated in the sandpits are featured in a Design Catalogue (Frohlich *et al.*, 2012)

3.2.2 Participatory problem-solving (PPS) workshops

A PPS workshop involves a 2 stage process: (i) knowledge sharing and (ii) problem- solving in relation to a specific issue or set of issues. Workshops with this format have been used successfully on the Sus-IT project to generate a documented result or solution to the problem or issues under consideration. Such output can then be used to inform further research, policy-making, practice and design relating to the issues.

Key to the success of such workshops is the careful planning of the structure and the process of the event to enable the sharing of knowledge, deep engagement in the issues, and then immersion in problem-solving (which is facilitated) and the documentation of the specific solutions or outputs produced through the collaborative process. After the usual preliminaries, these PPS workshops begin with information sharing presentations to set the context for the 'problem' and also to provide an opportunity for participants to work together in groups to review and refine statements of key issues or requirements emerging; to develop solutions and, where appropriate, a forward plan to implement these. Each group is allocated a facilitator, who was also part of the planning process for the workshop (and therefore has knowledge of the rationale, objectives, requirement for documented output etc.) and a rapporteur who keeps a detailed record of the deliberations which take place and the outcomes/agreed actions.

The Sus-IT/ KT Equal Workshop entitled 'Taming the Dragon' held at Anglia Ruskin University in November 2011 provides an example of successful use of this approach. This problem-solving workshop was convened explicitly to address ICT learning and support issues (identified by Sus-IT and other related research). Participants in the workshop were relevant stakeholders (many were older people and most were ICT users). They were invited to the workshop to work together first to produce a specification of their ICT learning and support requirements and then to develop an effective model or 'blueprint' for delivery of such ICT support which would enable them both to achieve and to sustain digital engagement. The carefully tailored and facilitated programme enabled the objectives of the event to be met successfully, namely:

- To achieve a consensus on the characteristics of current ICT learning and support provision available to older people;
- To elicit a shared vision of the ICT learning and support provision sought by older people (and informed by their experiences and preferences);
- To formulate a strategy for transition from the existing provision to the vision for future provision and a supporting "specification" for future learning and support delivery.

This workshop provided documented outcomes (statements of user requirements and a user-generated strategy for sustainable ICT learning and support for older users of new technologies and a plan to achieve implementation). Further details are available in monographs authored respectively by Mountain (February 2011) and by Damodaran (November 2011). The outputs were used subsequently to inform deliberations elsewhere of design and provision of ICT support in the community (see *Falling off the Bandwagon: Digital Disengagement 2012.* Available: http://www.stgeorgeshouse.org/index.php/download_file/481/226/)

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1. Sus-IT project overview.

2. Sus-IT briefing document: engaging older people in research and design.

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Sus-IT – Sustaining IT use by older people to promote autonomy and independence

Principal Investigators: Professor Leela Damodaran and Wendy Olphert, Loughborough University

Sus-IT is a 39 month Collaborative Research Project funded through the New Dynamics of Ageing (NDA) programme, by the five UK Research Councils - AHRC, BBSRC, EPSRC, ESRC and MRC (grant no. RES-353-25-0008). The NDA programme is the largest research programme on ageing ever mounted in the UK.

The rationale for the project - why is this research needed?

Growing numbers of older people are now using computers and the Internet for a wide variety of purposes and are enjoying the benefits of being digitally engaged. However evidence suggests that some older people do not, or cannot, sustain their IT use. As yet there has been little research to understand the factors which could lead to such 'digital disengagement'. The aims of Sus-IT have been to address this gap by generating new knowledge and understanding of the challenges facing older computer users, how these challenges affect their ability and motivation to continue using their computers, and what can be done to help older people to remain digitally engaged.

Approach to the research

To address these complex sociotechnical research questions successfully requires knowledge and expertise from a range of disciplines and perspectives. The project has been structured into a number of different workpackages, each of which has involved teams of researchers with complementary skills and from different disciplines, who have focussed on a particular aspect of the research problem. Our multidisciplinary research consortium comprises 22 researchers from eight UK universities, with expertise in participatory and user-centred design, psychology, gerontology, sociology, computer and information science, human-computer interaction, and learning technologies.

Older people themselves have been central to the research – more than 1000 older people from diverse backgrounds across the UK have participated in our project in some way. Key research users (e.g. organisations representing older people and those providing services and products to be used by older people) have also been included as collaborators in the research. The project has been guided by an Advisory Group and supported by a number of external consultants.

To achieve the project objectives, partners have applied an innovative combination of methods, tools and techniques with the aim of engaging older people and enabling them to shape and participate in the research. Methods and techniques used have included a survey of digital engagement, problem-solving sessions and workshops, co-design 'sandpits', interactive forum theatre, and testing and evaluation of software and product concepts developed on the project.

Key findings from our research

The Sus-IT digital engagement survey has involved approximately 750 participants aged over 50 from across the UK. Findings show that many older people are frequent users of a range of digital devices, including the computer/laptop, mobile phone, tablets and eBook readers. A large proportion of respondents report using a computer every day or several times a week. Survey results also show that although small numbers of participants use a tablet or a mobile phone to access the internet, a very high percentage of those that do use their device every day or several times a week to access the internet.

The most frequent challenges reported by older computer users were:

- a lack of technical skills/knowledge to do specific tasks or to solve problems when they occur;

- understanding technical 'jargon';
- remembering things – for example passwords, or all the steps in a process;
- physical difficulties – for example using the mouse or keyboard, or seeing the screen;
- not knowing how to deal with computer security, especially how to deal with/prevent unwanted content such as viruses, pop-ups and spam.

We found that older people value very highly the benefits and independence that computer use gives them, and they are often exceptionally tenacious in trying to remain digitally connected – persisting in the face of many obstacles such as those listed above, and often without awareness or use of existing aids to accessibility. When disengagement occurs it is often a gradual process, rather than a single event, and usually results from a combination of factors – particularly changes in physical ability, memory, support, and/or technology problems/changes. The availability of help and support is of paramount importance to sustaining connection. More than a quarter of respondents said that support from other people was the most important thing helping them to use computers effectively. Help and support is mostly gained informally from family and friends - formal learning and support provision is very varied and 'patchy' across the UK.

Outputs from our research
Our research has generated new understanding of the needs of and challenges faced by older computer users, and of potential solutions. Key outputs include[1]:

- identification of the phenomenon of digital disengagement as a fourth digital divide and of the risk factors that can lead to this phenomenon;
- an innovative suite of tools, methods and guidance for working collaboratively, participatively and ethically with older people in research and in the design and development of ICT-based products and services;
- an 'adaptivity framework' which has been applied to develop prototype software that helps to address problems encountered by people experiencing age-related changes in vision, dexterity and memory;
- a design catalogue of 40 product concepts aimed at the ICT industry to stimulate new product development for the older market;
- a user-generated strategy for provision of sustainable, community-based ICT learning and support for older people and a blueprint for design and implementation of such centres, with exemplars.

Over 60 publications have been produced by the project team which document these outputs.

Policy implications and future impact
The issues surrounding sustaining digital inclusion in older age are multi-faceted and complex – however addressing these will have significant benefits not only for older people but also for the economy and society. The range of potential solutions is diverse, with implications for ICT policy and strategies, as well as the design and delivery of ICT based services and products. Adoption of the solutions requires a coordinated change management approach involving a wide range of stakeholders. To promulgate the outcomes from Sus-IT and to achieve their implementation, project members are working with key players responsible for the delivery of government services and policy, commercial and third sector organisations and developers of software, equipment and ICT based products and services. A forward programme is underway as part of KT-EQUAL (a programme which aims to ensure that the results of extensive research are translated into real, tangible benefits for older people themselves).

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[1] Sus-IT project outputs and the full set of project briefing papers are available via:
http://sus-it.lboro.ac.uk/publications.html

An underpinning principle in the philosophy of the NDA is the engagement of older people as active participants in research – in contrast to being passive research 'subjects'. In Sus-IT they have been a core part of our research community. More than 1000 older people from diverse backgrounds across the UK have participated in our project in some way. To engage and empower them – and thus build capacity in this community – a range of different methods of engagement have been developed and applied. Collectively these comprise a Toolkit for engaging older people in research. The components are described below.

Working collaboratively with older people in established groups and communities of older people

In order to reach older adults in all their 'diversity', in terms of health and wellbeing, socially, economically, culturally and in terms of race and ethnicity, Sus-IT researchers have worked collaboratively with 33 established groups and communities of older people in the Midlands, Dundee, London, Surrey and Newcastle. A range of different activities and events have been undertaken with the different groups, depending on their interests. The aim has been to inform and engage older people with the Sus-IT research topic, to encourage their active participation. User engagement has been achieved in many cases through 'gate-keepers' responsible for provision of computer support or formal computer classes. Regular updates about project progress have been given to participants, e.g. through a periodic newsletter, along with sessions to present emerging findings and the outcomes of the project and to invite feedback from participants. Participants have found engagement with these events and activities rewarding. For example, one said:

"It is great to be involved in something that will make a difference to older people's lives."

(Mark, aged 67)

In March 2010, Sus-IT hosted an ESRC Festival of Social Sciences event for older adults and representatives from statutory and non-statutory organisations. The festival event 'Improving everyday life: getting connected to public services' was organized for residents from across the borough of Erewash over the age of 50 to come along to find out about the benefits of engaging with digital technologies. Case studies of the personal journeys of the digital engagement of five older people were collated and presented at the event and are also captured in a brochure produced for the event. Local Government and businesses were provided with an opportunity to demonstrate their services and show people how to access them online. Feedback about the event, both from older people themselves and from the organisations involved, was very positive.

Digital Engagement Study

A Digital Engagement Study of approximately 750 older people has been undertaken. This has generated new knowledge and understanding of the dynamics of ageing in relation to changing of ICT use and development. The focus is on how older people use digital technologies in everyday life, rather than on the technology itself. It proved necessary to devise a number of survey instruments to accommodate varying levels of literacy and wellbeing. The questionnaire was administered interactively in a supported process. Older people from the 24 groups identified above have completed the questionnaire.

Co-design workshops ('sandpits')

'Sandpits' were used to encourage effective engagement of older people in ICT design. These provided opportunities to explore current and emerging technologies in a playful and creative context through the use of technology demonstrators. The objectives were: to create awareness among older people of emerging ICT; to provide a supportive and empowering approach to participation; to help them envisage potential implications of these technologies in their lives; and identify key issues and user requirements for the older market to inform the development work of ICT designers.

A series of four linked sandpits were developed and hosted to enable older people to experience 'hands on' use of demonstrators, dramatic enactment of scenarios of demonstrator use and the redesign of the demonstrators through co-design sessions. The themes of the sandpits included 'Supporting memory and identity in later life' and 'Combating social isolation with new technology'.

A total of 66 participants were involved across the four sandpits and participants varied in terms of their marital status, education and occupation etc. Participants reported the 'sandpit' experience to be rewarding and worthwhile. For example one said:

"I think it's good to have to think right through something instead of just saying "I would like"... it makes you think all round the problem, which is very good, lateral thinking."

(Amelia, aged 68)

Interactive Forum Theatre
This method gives older people opportunities to explore aspects of current and emerging technologies in an entertaining and engaging format. It uses drama techniques to elicit user requirements through a combination of dramatic enactment of future scenarios and 'hands-on' engagement with working demonstrations. This can be done in live theatre or, where a lower cost option is necessary, by use of DVDs instead. At the end of the theatre production actors enter (in character) and participate in a question and answer session. This is a powerful way of raising awareness of issues, eliciting requirements and generating feedback for developers, designers and manufacturers.

Problem-solving workshops
This approach has been used to address ICT learning and support issues identified by Sus-IT and other related research. A range of relevant stakeholders were brought together in workshops to share knowledge, engage in focused problem-solving and co-produce specific outputs. These workshops were structured to provide documented outcomes (statements of user requirements and a user-generated strategy for sustainable ICT learning and support for older users of new technologies and a plan to achieve implementation).

Testing/evaluating software and hardware
A small sample of older people has also been involved in testing and evaluating the software "adaptivity framework" developed by the project.

A Toolkit for engaging older people in research and design
To assist researchers in providing a rewarding experience for participants while also gaining valid data, a guidance document has been developed which includes the following:

- approach and recruitment of research participants
- introducing and explaining the research task
- ethical aspects : participant rights, written consent, data protection and confidentiality issues
- the importance of (a) on-going support throughout the study (b) a de-briefing session and (c) feedback on outcomes/findings.

The set of techniques described above, together with this guidance document, represent a Toolkit for engaging participatively, sensitively and ethically with older people in research and design.

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Sus-IT Project

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