WHAAM Quality Final report

For the WHAAM project, quality related activities were performed collaboratively by all of the project partners across the entire work programme. A user-centred approach was taken, including efforts to consult with multiple stakeholders. The aim of the process was to enable the development of an application to support a complex process of ADHD observation in the natural settings which is usable and suitable for the context of use.

A range of methods were used to improve quality across the workpackages, including:

- Reviewing of existing literature.
- Reviewing of existing applications for behaviour monitoring.
- Collaborative review of the context-driven framework
- Collating a range of User stories from multiple participants
- Extensive paper and balsamiq prototyping by multiple partners to explore different parts of the design space, as recommended in the Human-Computer Interaction literature.
- Sharing of documents.
- Project meeting and teleconference discussions
- Stakeholder evaluations of paper prototypes (including ethics and qualitative analysis)
- Feedback on interactive prototypes
- Feedback on final results in E-Learning and training materials.

Results

Quality related activities were performed throughout the workplan. Planning and management of these activities was achieved through the quality committee and additional activities to consult with experts and stakeholders. In addition, two surveys were performed to feed information into the process.

Dublin Quality Meeting

Initial progress on the workplan was reviewed, together with the draft plan for quality activities, including a detailed breakdown of the user centered design activities within WP3. The need to specify a timeline for quality activities was noted, particularly with respect to WP3 where many dependencies exist with different workpackages. Key quality actions related to the need to obtain stakeholder feedback for multiple components of WP3. Actions to improve the quality of the final version of the framework document were identified, including re-organising the document and adding additional material.

Quality in Mental Health applications

This document set out a series of guidelines with regard the design and procedures for developing technologies for use in the mental health field, using the European Foundation for Quality Management (EFQM) Excellence Model as an overall framework. For technologies to be used in the mental health field, action research approaches can be used to ensure that user-centred principles are met. User-centred system development can involve amongst other activities and actions, the use of qualitative data collection, for example, observing the work of the end user and carrying out semi-structured interviews based on open-ended questions. Research activities that are recommended include making explicit the goals and outcomes that a system will seek to achieve; ensuring that collaboration occurs amongst end-users, designers, developers, and usability experts; and creating user stories, paper prototypes, and more sophisticated working prototypes.

Quality in WHAAM.

Building on this framework, this document sets out the overall approach to managing quality in the project, including the focus on quality *enablers* and *results*, the operation of the quality committee, policies, resources, and deliverables, and Work Package co-ordinator roles. Also included is a detailed breakdown of quality within each workpacgage, with analysis of dependencies and risk assessments carried out within each of the workpackages (and subsequently reviewed at each project meeting).

Greek Quality Meeting

As well as reviewing the two WP7 deliverables "Quality in Mental Health Applications" and "Quality in WHAAM", and ongoing review of quality activities in WP3, more consideration was given to WP4 (dissemination), in terms of reporting procedures for dissemination activity, and evaluation and feedback strategies for WP5 (training mateirals), and WP6 (E-Learning Module) in order to improve quality, and particularly the need for partners to review early versions of the materials. Within the management workpackage (WP1), the issue of communication was discussed including difficulties in accessing shared documents, along with actions which can be taken to improve communication within the project. As a result of this, a survey was presented in order to gather opinions from project partners.

First Partner Survey

The survey aimed to gauge satisfaction with communication in the development work packages, identify perceptions of risk to project delivery, and investigate the forms of communication that project partners wished to see. It was seen that partners thought communication could be improved across all activities, although communication regarding the framework development and prototyping activities was generally seen as acceptable or better. These activities were distinguished by the sharing of multiple drafts and versions of paper prototypes. Following on from this, in the communication format question, partners clearly expressed a preference to see more email updates and sharing of partially completed documents. There was also interest in more videoconference meetings. There were some concerns about the risk of delays to all workpackages. This is perhaps to be expected for issues such as dissemination, as this is dependent to a degree on the availability of the final application. Likewise for the e-learning and training workpackages, a dependency exists with the application development. Scope was seen for improvement in management, quality and dissemination work packages, and efforts were made to do this across the project.

Final Meetings and Second Partner Survey

Quality issues were discussed at the Porto and final (UK) meetings. The communication of prototypes and sharing of partially completed work was seen as significantly improved. The work of the development teams on the mobile and web applications was commended, along with the timely production of the training materials and first version of the e-learning module by the Portugese partners. These reduced significantly the risks facing the project, allowing the partners to concentrate on improving the quality of the final deliverables. A small survey was conducted in order to ask partners which forms of feedback they wished to see in the remaining period, partners expressed a wish to see both internal and external expert feedback as well as end-user feedback.

Innovation and Learning

Many of the lessons learned from the quality activities are spread across the work packages of the project. We include here some lessons learned from the evaluation of early stage prototypes with stakeholders and the subsequent transcription and thematic qualitative analysis of this data, as they are relevant to the project at a high level and are not directly represented in the other deliverables.

The findings from qualitative interviews were themed into seven categories with emphasis given to ideas which were most common among participants. The following sections explore the issues which were present in the interviews (varying practices in ADHD, difficulties generally with observation/gathering information, need for simplicity, benefits generally, concerns regarding data security, concerns regarding management/responsibility, and suggestions for change). The following sections explore these topics in greater detail (pseudonyms are used to identify participants).

Varying Practices in ADHD

Teachers, parents and clinicians had a variety of experiences around the process of ADHD identification, diagnosis and support. Participants tended to point out that the quality of care depended greatly on the clinician that you saw and that they tended to be involved with several clinicians before receiving a diagnosis.

Jennifer, a parent whose son has ADHD, was generally positive about the diagnostic process and how fast the process was, saying "… So then his first class teacher then said to refer him to get the diagnosis and then the diagnosis was pretty quick after that." At the same time, many participants pointed out the limited resources and the lack of continuity of care, pointing out how they may not see the same clinician each time they have a check-up.

Donna, a teacher and Nicola, and teacher and psychologist, suggested that care can vary depending on the psychologist involved and the organisation providing support and care. Donna said that it depends on the psychologist and that some would be very good and others would not. Nicola pointed out that practices varied depending on the organisation as well.

Ava (teacher) and Susan (parent) mentioned some particular difficulties with clinicians due to limited resources and a lack of knowledge around the condition. Ava said that in her school they would rarely see clinicians and that there were limited resources generally and that children with suspected ADHD would often not be prioritised to be assessed by the school psychologist.

Susan's experience as a parent was that her daughter was left undiagnosed because their primary care physician was inexperienced in the area of ADHD and believed it was a condition that could not be diagnosed in girls. At the same time, as a parent, when she became better informed about the condition, she realised the pattern of difficulties matched those her daughter was exhibiting.

Overall, there seemed to be a variety of different practices in Ireland and the UK. Interview participants spoke about some of the difficulties around resources (clinicians and teachers not having the time to carry out observation) and there were suggestions that some clinicians may not be very knowledgeable about the condition, which negatively influences standards of care.

Observation and Gathering Information

During the interviews, participants were asked about their role in gathering information on behaviour and completing behaviour observation. None of the parents had been involved in gathering real-time information, but spoke about answering questions and completing checklists for clinicians. When this was probed further and parents were shown sketches of a system to support ABC and Frequency Recording, none were aware of these types of behavioural observation.

Clinicians and teachers, on the other hand, tended to be more aware of behavioural observation generally said their procedures varied depending on the nature of the case, their own experience, and where people worked. At the same time, some teachers, like Max, for example, who worked as a teacher before he trained as a psychologist, said that when he was a teacher he was not aware of any types of behavioural observation tools.

Jim, a clinician, felt that behavioural observation was not the standard practice in his place of employment. He pointed out that behavioural observation did not always occur as part of the diagnostic process, rather clinicians tended to use their own judgement about whether it might be useful.

Those who did carry out behaviour observation tended to describe how difficult it was to carry out, in particular that it takes a lot of time to complete and that is hard to ensure multiple observers are taking note of the same behaviour. Donna and Concepta suggested it was difficult to set up properly and make sure that those completing the observation were consistent.

Those who had worked in classrooms, as teachers or special needs assistants, pointed out how difficult it was for a teacher to attend to the students, deal with the behaviour, and continue to teach, as well as observe. Max and Olive's comments illustrate this point that teachers find it difficult to complete direct real-time behavioural observation.

Notwithstanding the difficulties around finding the time to complete behaviour observation, teachers and clinicians interviewed tended to recognize its importance and gravitated towards a naturalistic approach. For example, many spoke about going into a classroom and simply writing a narrative of what occurs.

In summary, none of the parents interviewed had been involved in gathering real-time information, and clinicians and teachers tended to be more aware of behavioural observation generally but noted their procedures varied depending on the nature of the case, their own experience, and where they were employed. Most tended to gravitate towards a naturalistic and narrative approach due to the amount of time and training it takes to set up and carry out a more complex type behavioural observation.

Need for Simplicity

Asked about technology and using a mobile application to help in behaviour observation, participants pointed out the need to have a very simple and easy-to-use application that takes minimal time to start up. In the early sketches, a large amount of detail was included which many participants felt was un-necessary. For example, from the user stories, information about the child's family background, names/ages of siblings, relationships with their siblings, etc. was included. Ava, a teacher, discusses the page which involved the background information on the child, pointing out how it was unnecessary for a teacher to fill in that information.

In addition, with the initial sketches of ABC behaviour recording, we included information about the place of observation, date of observation, name of observer, names of other people involved, general notes, and recommendations. Sinead, a psychologist with previous experience in applied behaviour analysis and functional behaviour analysis, noted that she would view the application as an adjunct, not a replacement for a psychological report. As such, she noted that the detail included in the initial sketches (of the date of diagnosis, history of difficulties, history of visits to a clinician, etc.) was unnecessary. Others, including Concepta (an ABA tutor), Sofia (a teacher) and Emma (a psychologist) spoke more generally on the need to have a simple and easy-to-use mobile application.

Overall, participants pointed out the need to have a very simple and easy-to-use application that takes minimal time to start up. Participants made suggestions about reducing the amount of words, including pictures, and making the interface very intuitive and easy to use

Benefits (Generally)

Interview participants spoke generally about the potential of a mobile application for streamlining the process of gathering observations and helping inform interventions and improving communication between home and school. Many pointed out how having an application on a mobile device might compel a teacher to consider behaviour and that automatically generated graphs / charts could be helpful.

All of the parents and some of the teachers interviewed spoke about the potential for a mobile application helping to improve communication between school and home. Teachers tended to communicate with parents using notes home, phone calls, or regular parent-teacher meetings. Many suggested that a shared application could help communicate about the child's behaviour across the day and incorporate both positive and negative things that occurred.

In summary, parents, teacher and clinicians saw the potential of a mobile application for streamlining the process of gathering observations and helping inform interventions and improving communication between home and school. Many felt that automatically generated graphs / charts could be helpful.

Concern: Security of Data

One of the main concern interview participants had was around the security of data stored on a mobile application. Some, like Ava Andrea, and Sinead were hesitant about using personal information on a mobile application and where data would be stored, noting issues relating to the confidentiality of information about the children they work with, for example, that another child could access the information or a third party might be able to retrieve sensitive and personal information about a child.

Others, like Emma, Nicola and Mary were more open to the idea of having a child's name attached to the mobile application. They pointed out how the current practice, using paper-and-pencil tools, is to use real names or to use a type of code or pseudonym to identify the child. They also pointed out that computers and technology are already being used to record information about children.

In summary, there were mixed opinions about the security of data in a mobile application for supporting observations.

Concern: Management/Responsibility

Another consideration or concern that participants brought up regarding the mobile application was how difficult it would be for teachers, parents, and clinicians to find time to invest in properly using the tool. Jeannette, a parent said that it could take a lot of time to use technology and that it could be difficult to do in the actual moment when her child was having behavioural difficulties.

Teachers tended to have the same concern, noting they would have over thirty children in their class and when there is a behavioural difficulty, they are trying to make sure the situation is dealt with and that children are safe rather then trying to record what happened in the incident. Teachers Ava and Andrea said that using technology in the classroom could be difficult, because their attention would be divided between trying to teach, trying to observe a child, and also using the tool to record behaviour.

A variety of participants (parents, teachers, and psychologists) pointed out the need to have training and also for someone to take control and use the application appropriately to ensure it is beneficial for the child/teenager involved. For example, Susan noted that it would be important that someone was responsible for collecting and analysing the data collected in order to ensure it is used to implement changes.

Lynn, a psychologist, suggested some training would need to be provided to parents, teachers, and clinicians to help them use the technology appropriately. She said that without open communication and training for all users, categories could be misinterpreted and lead to misunderstandings.

In conclusion, participants suggested the need for proper training in order to use a piece of technology for recording behavioural incidents and also suggested it might be difficult for teachers, parents, and clinicians to find time to invest in properly using the tool. Management and responsibility for such a tool will be of primary concern when it is being used to support behaviour management of a child in school, home, and other settings.

Extra Issues and suggestions

All of the participants were asked whether generally they felt anything was left out of the mobile application or whether there was anything additional they felt might be useful. A number of participants suggested changes/amendments to the mobile application, which were incorporated into the tool. These additional elements are organised under subheadings that follow and include the following:

- Involvement of the Student
- ABC Charts (Free Text or Categorical)
- Retrospective Report & Additional Features

Involvement of the Student

Many participants spoke about the need to have the child/young person involved in the behaviour recordings. Several of the psychologists interviewed discussed how they would try to involve the child, parents, and teachers in coming up with solutions to support positive behaviour and promote emotional well-being. Jennifer, a parent, noted that it was important to involve the child / student to encourage them to take ownership of their behaviour.

Other suggestions participants mentioned included having a reward chart linked between the school and home; having the student self-monitor; and giving the student the opportunity to feedback when there is a behaviour incident. Jim, a clinician suggested simply having a teacher take note of positive behaviours could be a way of creating an intervention and promoting desired behaviour:

ABC Charts

When sketches were first created, there was a discussion about whether ABC charts could have predetermined categories or whether they needed to be left open to allow the user to write in a detailed description of the behaviour. While not all participants had an opinion on this, Sinead, Nicola, and Emma commented and made suggestions. Nicola and Emma had some concerns about having pre-determined categories and preferred open fields to allow a teacher/parent to describe the behaviour in detail.

Sinead, on the other hand, when shown the ABC charts with predetermined categories, thought this would make it easier and quicker to use. She noted that teachers and parents might find this style of form easier to use and might therefore be more inclined to use it. She further suggested that there could exist a feature to automatically suggesting reasons behind why a behaviour is occurring.

Retrospective Report & Additional Features

As mentioned earlier, parents and teachers spoke about the potential for a mobile application helping to improve communication between school and home, but many had concerns about the amount of time that could be taken up completing observation. Jennifer [parent] and Andrea [teacher] suggested a retrospective way of reporting on behaviour.

Dissemination and Exploitation

We consider below some of the issues which can effect the future dissemination and exploitation of the project results.

Guidelines and practices surrounding monitoring

Debate exists in the fields of psychology and psychiatry about the best practice for diagnosis, monitoring, and treatment of ADHD. Researchers and clinicians have acknowledged that a lack of clear cut-off points or physiological test makes diagnosis complicated. In addition, there are debtes around best courses of treatment and care (e.g. medication, psychotherapy, or a combination). A number of guidelines concerning the diagnosis and multimodal treatment of ADHD exist, including the AACAP, AAP, and NICE:

- American Academy of Child and Adolescent Psychiatry (AACAP): Practice Parameter for the Assessment and Treatment of Children and Adolescents with Attention-Deficit/Hyperactivity Disorder
- American Academy of Pediatrics: ADHD: Clinical practice guideline for the Diagnosis, Evaluation, and Treatment of Attention-Deficit/Hyperactivity Disorder in Children and Adolescents
- UK National Institute for Health and Clinical Excellence (NICE) guidelines: Attention deficit hyperactivity disorder: Diagnosis and management of ADHD in children, young people and adults

Each of these guidelines refers to the DSM diagnostic classification system and provides recommendations for the assessment, diagnosis, and management of ADHD. With regards assessment, each emphasize how a qualified clinician must evaluate symptoms while considering alternative explanations for the behaviour and must consider how these symptoms interfere with functioning in more than one setting (e.g. home *and* school). However, there are slight differences in the guidelines. For example, the AACAP and NICE guidelines emphasise a need to obtain detailed information social and family history and circumstances; but the AAP guidelines suggest more generally that a clinician needs to obtain 'reports from parents'. Another key difference in guidelines regards behavioural observation and the extent to which a clinician must gather evidence of behavioural difficulties. The NICE guidelines are the only document to specifically mention direct behavioural observation, others state the requirement for consultation with the school alongside parent/guardians and include in this the need to gather information from parents/guardians teachers about a child's behavioural presentation.

Resources and best practice

Review of the early stage prototypes discussed above, together with expert review of the application and e-learning materials raises a number of risks with respect to future dissemination following the end of the project. In particular, the strong assumption of a best-practice workflow is dependent on the availability of trained health professionals, and the appropriate level of resources being available

for each child. Engagement with stakeholders showed that this is sadly often not the case. While the project itself can do little to rectify these systemic failures within the provision of psychology supports to children with ADHD, a case can be made for introducing support for more flexible delivery.

Intellectual Property

A significant risk to fuure dissemination and exploitation is possible encumberance by Intellectual Property restrictions, particularly given development by partners in mulitple institions where each might have their own policies on Intellectual Property, and differing availability of specialised staff to deal with IP issues. Following extensive discussion, a decision was made to use a permissive open source license (MIT License) to facilitate future exploitation of the project results by (a subset of) the project partners or any other party interested in taking the application forward. This was seen as the most sensible outcome from a scientific and educational perspective.

Taking this approach to intellectual property, it is vital that appropriate publications are produced now that the final project deliverables are available, both in terms of providing evidence to facilitate uptake, and to ensure that appropriate recognition of the efforts of the Partners and the support of the European Agency is given.