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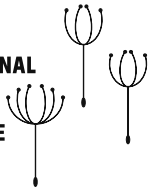
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The AIR model (Activities, Internal world, Relationships): a pragmatic framework for evaluating co-design

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Abstract: A pragmatic model, AIR (Activities; Internal world; Relationships), is presented for co-design of technologies and products to support well-being of

people living with dementia. This model, co-developed with people with lived experience, is aimed at including psychosocial aspects in the prototype development process. The model is then related to a form of mindful evaluation framework that can be employed during the prototype testing of co-designed solutions. The components of this evaluation framework and associated instruments are described.

Keywords: *dementia; evaluation; co-design; mindfulness.*

1. Introduction

The increasing pressure for participation by people with lived experience in all areas of public decision-making is reflected in the mantra of 'nothing about us without us.' Co-design and evaluation processes in the realisation of well-being and healthcare products must aim to honour this.

MinD (Designing for People with Dementia: mindful self-empowerment and social engagement) is a European Commission funded project under the Marie Skłodowska-Curie Research and Innovation Staff Exchange (RISE) programme between multiple international partners which is co-designing products for use by people living with dementia and their carers. MinD is comprised of researchers, designers, practitioners and others who may also define themselves as a group of people with and without lived experience of difficulties related to memory, cognition understanding and brain functioning, including various conditions of dementia.

The process of design in MinD has been based on the lived experience of people who have problems, difficulties and things to say related to dementia and with people who support them in daily life. Learning from what they have shared about their lives, MinD's co-design and co-creation processes have taken nearly four years to date and have involved collaborative work across Europe.

The project has fostered 'mindful' co-design which intends to create technologies based on wants, needs and aspirations, to support the wellbeing of people living with dementia and other problems of memory or cognitive impairment, through enhanced opportunities for social engagement, self-empowerment and mindful meaningful occupation (Niedderer et al., 2017). It is important to stress that the MinD team are all co-designers and co-researchers rather than two distinct groups; the 'experts' and the 'people with problems'. Our partnership and the mutuality it embodies have produced a number of new models and principles to extend across the entirety of their design method stories.

This paper first outlines a model, AIR - consisting of Activities (or actions); Internal World (feelings); and Relationships – that we have developed for mindful co-design. We describe aspects of its development and then illustrate how it has been applied in the evaluation of one of the MinD prototype products.

In a conventional evaluation for products aimed at supporting the wellbeing of people with dementia, it is the dyad of the individual living with a condition and their carer that is often

considered. For social solutions, a broader social network will become relevant and, where technology solutions have been proffered, the relationship of a design solution with the human dyad is considered to be of growing importance (Cudd et al., 2013). Previously, a number of existing evaluation approaches have been proposed and explored, some of these based on quality of life measures which are mostly clinical or concerned with psychosocial well-being, (Craven et al., 2014, Stoner et al., 2017) including measures such as Psychosocial Impact of Assistive Devices Scale (PIADS) (Day et al. 2002). Others are concerned with broader well-being concepts such as 'salutogenesis' which have been applied to dementia (Alm et al., 2015) and some are more closely associated with the technology adoption models (TAM) (Chaurasia et al., 2016).

In co-creating evaluations, it is essential that the questions asked reflect issues and values of importance to partners with lived experience as well as those of trained researchers and assessors and furthermore that the context of the evaluation is empowering for everyone (Advocacy in Action 2006, Gosling and Martin 2012).

Evaluation of MinD's outputs aims to be an extension of the holistic process of the co-designed technologies which aims to be, in itself, both a collaboratively produced and mutually enabling process.

2. AIR; a co-design model

MinD's design processes have guided the co-design and shared evaluation of wellbeing products that aim to capture domains of social interaction and mindfulness in the daily lives of people living with dementia. MinD's central focus on lived experience prioritises participants' direct interface with the product and any subsequent impact of that experience upon their relationships with their external environments, and with their own internal worlds. It is represented diagrammatically in, Figure 1, by the AIR model (Activities; Internal world; Relationships), which enhances the exploration of the user experience with a dimension of mindfulness.

The three components of AIR are closely inter-related. Thus, for example, a lack of activities can have detrimental effects on both the internal world and on the relationships of the person. Turmoil or distress in the internal world can prevent someone participating in enjoyable activities and over time can harm relationships. Negative and positive external influences on any of the AIR components are represented by red and green arrows respectively. A more obvious measure of success from design is perhaps a solution of providing or supporting a new beneficial activity or the maintenance of such, but there are also things that can be done with design that are aimed at improving the overall experience including relationships with people or environments, or enhancing the internal world of a person living with dementia.

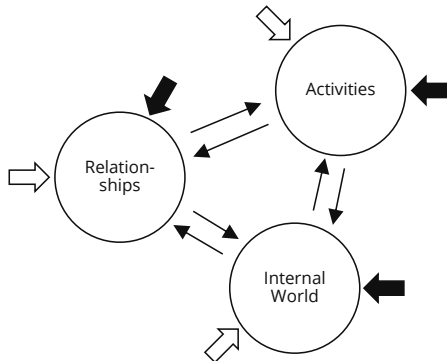


Figure 1: The AIR model with mutual interactions (thin arrows), negative external influencers (black arrows) and positive external influencers (white arrows)

We suggest that this model can help in three ways:

- *it is consistent with a mindful approach to design as facilitating experience.* It reminds us of the importance of bringing the internal and external worlds together and, as there is no specific dimension of time, it rests in the moment.
- *it informs co-design.* In designing with and for people with dementia, we can consider all three components specifically. We may for instance use design that is focused on one component, such as activities, but in thinking about how the design may work we can take into account the likely impacts on relationships and on the internal world. Or designs can be targeted at either of the other two components. In practice, it may be a combination of targets, but again we can be deliberate in our intentions if we think simultaneously about all three parts of AIR.
- *it informs evaluation.* This means working collaboratively to decide the suitability of prototype designs for people living with dementia (and those closest to them). The three components of AIR give us a framework that we think will be useful in assessing not just whether something is effective but also *how* and *why* it has that effect. Or, conversely, if it doesn't work, why not - which will give us a handle on how to improve it

3. The origins of AIR

In aiming for co-creation in design, the MinD consortium has needed to adapt widely; to capacity-build among all of its partners, to make mutual travels along uncharted trails, to learn from raw experiences, to work out of comfort zones and to find new ideas in unexpected sources. The MinD evaluation framework and its AIR model can be tracked through some of these exploratory journeys.

Exploratory workshop: 'Talking about textiles'

Preceding the co-design activities leading to the MinD prototypes, we introduce one early exploratory workshop that helped people with lived experience to understand basic design concepts through enjoyable tasks that related to textiles as technologies. In the session, a miscellany of textiles, including clothes, fabrics, swatches and soft furnishings, were available for participants to touch, smell, drape, manipulate creatively before considering their attributes, appeal and applications within people's lived in worlds (external and internal). People's findings about textiles are shown in Table 1 and Figure 2. In retrospect, this activity was one of the activities in MinD that heralded the development of the AIR model, in exploring people's inner- and outer- world relationships with textiles and their actions and activities concerning them.

Joint capacity building event: 'Let us in we're co-designers!'

The next stage was a full-day workshop, held in March 2018, that enabled partners with and without lived experience of dementia to work creatively together to examine their relationships with everyday objects prior to commencing design considerations for the MinD technology prototypes. The event began with tasks that demonstrated common social abilities and difficulties, regardless of impairment or diagnosis. This helped everyone to appreciate one another and begin to work together in teams.

Participants then considered memory aids and connective devices; smart phones, paper diaries, maps, apps, calendars, and a handkerchief with a knot in it (reminder!) They commented on design quality, aesthetics, possible improvement / modification, effectiveness and impact on external and internal lived in worlds (see Figure 3).

The process and outcomes of this workshop assisted to direct MinD to the importance of multiple systemic relationships between assemblages of people with one another and with objects within their lived in networks. The understandings of this were encapsulated in and navigated all future thinking through AIR.



Figure 3: MinD co-design Workshop

The template shown in Figure 4 reflects some of the criteria that people thought about in relation to their smart phones. Here, participants recognised that this helped them to think about familiar objects in their everyday lived in worlds, to see them anew, view them critically and consider how design factors impacted upon their relationships with people, with objects and processes, contexts and environments and with their own personal and innermost worlds of thoughts feelings, perceptions.

It was from the kinds of discussions in this workshop that it became apparent that the impacts of design could be usefully separated by looking at the user's activity in relation to a product, at how it affected them internally (how it made them feel), and how it affected their relationships and functioning in the external world. This then led by a process of reflection to the diagrammatic version of AIR presented above in Figure 1.

A		I		R	
User experience of an activity with an object		internal world relationship with self feelings/thoughts/perceptions		relationship with world interface with other people, things and environments	
ACTIVITIES ACTIONS ATTRIBUTES:	Y/N	GIVES ME A SENSE OF:	Y/N	IMPROVEMENTS:	Y/N
Efficient		Self Esteem		Makes Me More Productive	
Useful		Security		Helps Me Perform Well	
Stylish		Confidence		Improves My Social Networks	
Practical		Being 'Trendy'		Increases My Capability	
Easy to Use		Relief From Embarrassment		Promotes My Independence	
Complicated		Relief From Confusion		Enhances My Quality Of Life	
Need Help With		Relief From Frustration		Helps Moderate My Confusion	
Awkward To Use?		Relief From Frustration		IMPACTS UPON MY:	Y/N
Would Need To Learn Stuff Before Use?		Happiness / Contentment		Willingness To Take Risks	
It Seems To Have Potential		Peacefulness		Ability To Join In	
		Purpose		Motivation To Socialise	
		Being In Control		Eagerness To Try New Things	
		Being Accepted		Ability To Take Advantage Of Opportunities	
		Being Empowered		Facility To Be Mindful	
		Togetherness With Others		Physical Well-Being	
				Emotional Well-Being	
COMMENTS		COMMENTS		COMMENTS	
<i>"I had a Christmas gift, a brand new smart phone, my son gave it to me, but it is still in the box six months later, because nobody's shown me how to use it."</i>		<i>"I feel quite confident and in control when I have my phone to hand."</i>		<i>"makes it easy to get in touch with my friends even when I can't see them."</i>	
<i>"I think it could be made easier to handle"</i>		<i>"I do feel confused and inadequate because there are so many settings."</i>		<i>"I don't know if it helps me take risks because I stay away from risks."</i>	
<i>"I have a great idea for a holding frame - light and quick to operate"</i>		<i>"It might can possibly help me to feel more accepted with the grandkids"</i>			
<i>"sometimes simple is best"</i>					

Figure 4: Template with related participant comments relating to mobile phones

The various workshops and other capacity building sessions we have facilitated have helped to seed a culture of creative co-design for all of the MinD partners, through:

- enabling a mutual and mindful appreciation of experience and expertise
- fostering a strengths and opportunities perspective
- building a shared language
- taking shared ownership and shared responsibility
- seeing problems and solutions through many eyes

These workshops were also part of the process that fed into the development of an evaluation approach aligned to the co-design process. In particular the MinD project had used the emergent AIR model in the process of developing two technologies: *Lets Meet Up*, a digital screen interface to enable social connections and activities, and *The Good Life Kit*, a compendium of serious games together with a book of information, reflections and mindful exercises. We now focus on the development of the evaluation process, focussing on evaluation of the *Good Life Kit*.

4. AIR and the Good Life Kit (GLK)

The aims of the co-designed and co-created Good Life Kit games and activities are as follows:

- encourage us to lead mindful lives
- enable us to empower ourselves
- assist us to engage in purposeful activities
- allow us to better connect with ourselves and with other people

Mindfulness is the relationship we have with our own experience. Self empowerment enhances a sense of agency, personal independence and control. Purpose fulfilled, gives meaning to our lives and those of others. Establishing better connections with self and the social worlds that we inhabit nurtures a growth of body and spirit.

The Good Life Kit (GLK) has 3 components:

1. *Living the Life: making the most of it*: a work book and aid to positive reflection and appreciation, to support living well with dementia It also incorporates 'A Walk Around Myself' tool: a set of mindfulness exercises to the use along with the workbook.
2. *This is me*: a social board game to facilitate forward and backward reflections on life experiences, appreciating the past and looking positively forward.
3. *You and me*: a dialogue board game in two parts to assist the deconstruction of relationships and daily living ('let your life flourish'), help examine feelings ('personal reflection'), enable pragmatic conversations around power and responsibility ('letting go'), and negotiate life problem areas ('the dialogue'). This

is a team game, to be played with chosen close and trusted 'others' who can offer advice and support within a safe space of shared decision making.

In considering how well the games and activities of the GLK work, it is important to be able to question ourselves and others through being present in the moment; what we notice, feel, experience, perceive; what actions we take and what all this prompts us to think about. GLK evaluation explores our actions, our inner experience and our relationships with people and things in our lived in environments, by utilising the framework of AIR.

5. AIR and the Good Life Kit evaluation

Holistic assessment of the GLK prototype mirrors the AIR triangle through its overarching theme of mindfulness as the connection we each have with our own experience. The evaluation method is centred around observation of the components of the GLK as they are being used and subsequent reflections and interviews to record the users' experiences. The MinD evaluation tool captures not only the user-activity interface with the set of board games and associated material that form part of the GLK, but also facilitates an added reflection of the games' influence on players' inner selves and the potential impact of players connection with their external worlds; and it additionally explores the game-play impression on any observers and evaluators. Thus, all three components of AIR are explored in this process.

It is through mindful connection with such experiences that game players, observers, supporters and researchers with and without dementia question themselves and others about what they notice, what they experience, and what this prompts them to reflect on. The values of co-design thus extended into and enriched the stages of prototype testing and evaluation of the GLK.

The interview is a mutual task where we support one another to share thoughts, feelings and suggestions in response to questions asked of us. Game players, in groups or individually, respond to questions with an interviewer or a supporter. Furthermore, (with game players' permission) the information gathering process extends wider; interrogating the interviewers, observers and the people there to offer support, who are all invited also to make observations about how they perceive the games and activities to meet the stated aims of the Good Life Kit, the wishes and needs of game players and also any other emergent purpose (as yet undiscovered).

Additionally, interviewers and any person there to assist the game players, (family, friends, carers or supporters) are then asked to make their own reflective journey, to discover how experiencing both the game and the game players engagement with it impacts on their understanding of the participants and the situation, what personal feelings emerge for them as observers and any potential for change that is liberated. Lastly, everyone invited to feed back on the interview process through a brief survey,

Thus, interviewer and supporter join with game players as mindful investigators, reflective and creative architects of mutual well-being and collaborative agents for positive change and possible further innovation. These dialogues become the shared space in which questions are asked and answered, observations noted and thoughtful insights distilled. This process tests the GLK from a multiplicity of different perspectives and enables our empowered journeys of self-discovery and appreciation of one another as co-evaluators travelling together.

To support the interviews, there are several tools that include:

- The story of MinD as a co-creation project and process, embracing its purpose and describing the products and how they came to be chosen and developed from the ideas, wishes and needs of people with lived experience. This was all written in the first person e.g. 'the aims of the Good Life Kit games are to encourage us to lead mindful lives; enable us to empower ourselves; assist us to engage in purposeful activities; allow us to better connect with ourselves and with other people.'
- Definitions of MinD principles e.g. mindfulness as the relationship we have with our own experience; self-empowerment as the enhancing of personal independence, agency and control; purpose meaningful occupation as the bringing of life fulfilment and improved social connection to nurture the growth of body and spirit.
- Key statements of permissions and rights for all participants, such as the right to refuse to answer, the freedom from judgment or negative comeback and the firm guarantee that this is not an assessment or a diagnostic test and that there are no right or wrong answers.

These tools are written in a strengths-based language throughout, and have tried to avoid needs-deficit or clinical wording and concepts. Additionally to support evaluation, the following materials have been produced, which are more typical of a standard semi-structured interview process:

- Participation information for the evaluation and consent forms.
- Evaluation questions and general guide to use, for participants.
- Guide for facilitators/interviewers.
- User friendly prompts
- Feedback questionnaires about the tasks and the session for all.

The questionnaire was designed to be user friendly and is split into four sections:

1. the first part elicits personal demographic data and information about personal wellbeing. It also includes a mindful question on feelings in the moment
2. secondly, pragmatic information about the game and game play is gathered; attractiveness, ease of play, accessibility; dimensions of the board game

3. the third section captures personal feelings evoked during game play (such as joy, regret, hope, sadness, excitement, anxiety, contentment)
4. the final section considers what potential impact game play could have on players interface with their lived-in worlds - enhanced social interactions, problem solving opportunities. (This requires some forward thought, although observers may detect observable signs of change during game play.)

The observation sheets capture what observers notice rather than recording direct verbal answers to questions. Observations convey information to the observers and others that can assist a mindful insight into the game-play.

Additionally, observers, interviewers and supporters are asked to 'notice themselves' to capture their own reactions and to reflect on the feelings and thoughts generated when experiencing the activity of others. This allows for insightful and mindful reflections that may serve to challenge or reinforce existing understandings about people's conditions and capacity or to develop new wider understandings about potential and opportunity in relation to people living with dementia, and the things that enhance or inhibit these.

6. Summary

The GLK development and the subsequent development of an evaluation tool for its prototype have been influenced by the AIR model, enabling it as a wellbeing product to concentrate on significant domains of Actions, Inner world (feelings) and Relationships within the lived experience of people with memory and/or other cognitive difficulties, including dementia. The Good Life Kit, along with other MinD technologies, serves primarily to assist and support people with dementia and those who are closest to them. Nevertheless its mindful aims and benefits encompass everyone involved in creating the kit, using the activities and games, or supporting their use by others. The GLK also has the potential for use in other health or social care settings, besides its original intended application to dementia.

Evaluations are presently being conducted across the four European countries that have gathered source data from participants living with dementia and their care givers. Evaluation contexts have differed from country to country; using clinic, care home and informal spaces. Formats have also varied between focus group and one-to-one interviews. In two countries, Spain and the UK, the evaluations have involved people with lived experience as active facilitators, interviewers and supporters. Early results demonstrate a very positive response to both the games and game play and to the creative processes of their evaluation. Particularly in group settings, there have been instances where we have observed previously silent participants noticeably 'light up' and engage with joy in game-play while their care givers then sit back and relax..

Findings from evaluation are giving interviewers, supporters and researchers much room for reflection. For example, those spaces where participants have recalled pain and held it for one another, fly in the face of conventional reminiscence advice to steer game-players

away from 'negative' memories'. Additional potential has been demonstrated for employing the Good Life Kit as a communication and awareness raising tool for care and support workers. Value has also been shown through game play for people living with other long term physical and mental health conditions, including cancer and strokes.

For the purpose of this paper, it is our experience that the Good Life Kit and all the processes and models it incorporates, especially AIR, can encourage each one of us to take a reflective and evaluative co-design journey. Whether we are engaged in information gathering, designing, evaluating a product or making use of the games and activities in our lives, we can each see ourselves as adventurers, explorers and discoverers. And throughout the co-design travels, it is our conscious connection with AIR that empowers all of us who participate in MinD, regardless of ability, capacity or difficulty, to mindfully live our lives and to flourish.

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