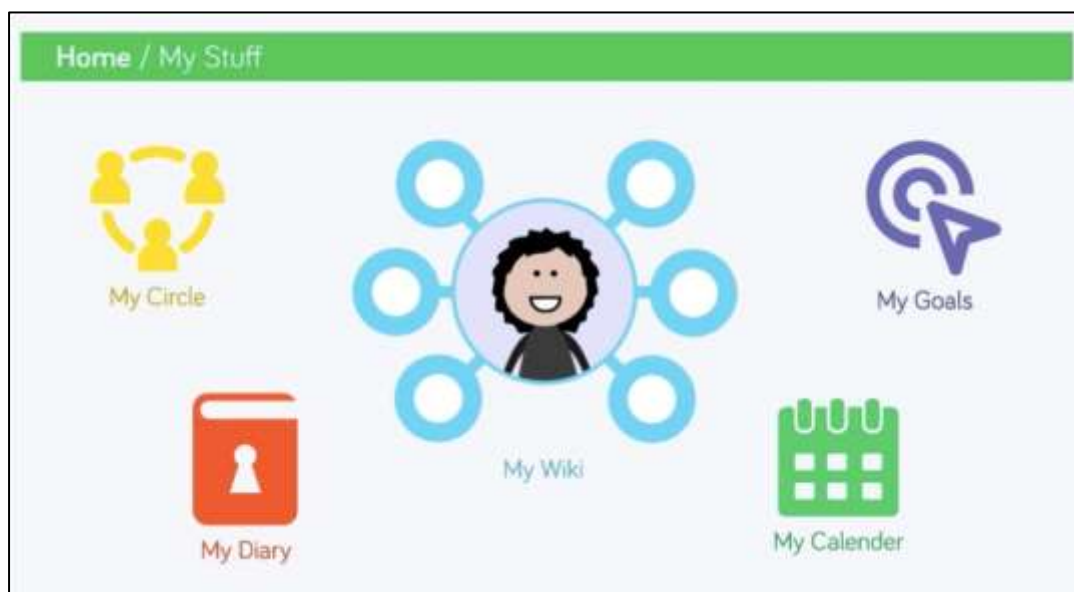


# Herefordshire Multimedia Advocacy Implementation Pilot

Interim Report April 2019



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# Herefordshire Interim Report April 2019

## Introduction

This Interim Evaluation Report has been prepared by RIX Research & Media at University of East London. A full evaluation method is being applied to the WikiMe project from which a Report will be produced at the end of the project's Pilot phase, which has been re-scheduled for publication June 2020 to accommodate the extension of the programme.

The WikiMe project evaluation approach is aligned to key goals of the DfE's SEND Reforms (2015) via a set of simple research questions on the effectiveness of WikiMe software use to influence:

- **Engagement** of individuals with SEN and disabilities, their parents & carers, professionals and volunteers in the co-production of personal plans for education, health and care and;
- **Impact** upon the quality of:
  - **Communication** between individuals, parents and carers with professionals, its frequency and quality;
  - **Self-advocacy** for children, young people and families;
  - **Personalisation** of the service provided meet the individual's specific needs, choices and aspirations in a way that is more 'person-centred'

Evaluation data has been gathered to date from 15 baseline and 3 midpoint questionnaires; 12 telephone interviews, 8 face-to-face interviews and 2 focus group sessions with 21 parent, carer and professional participants. A multimedia 'Easy Survey' questionnaire has been used with 14 young people taking part and analytics data of usage of the WikiMe Software has been analysed from 3 quarterly reports (Oct18/Jan/April19).

This Report provides a summary of the project's progress and status (April 2019), mapped to the project research questions, to assess effectiveness of the intervention. This is measured in terms of take-up of the software and the multimedia advocacy approach and consideration of the evidence that intended impacts are being realised on the project. The Report also presents the expectations voiced by the parents, carers and professionals taking part in the project alongside our findings to date. This interim evaluation process has helped to focus project goals for the team, providing a snapshot of the challenges parents and carers face with services that they anticipate the software could help resolve and identifying the drivers and barriers affecting the implementation of the multimedia advocacy approach in Herefordshire.

## 1. Engagement - expectations and experience of participants

Parents, carers and professions across Herefordshire attended demonstrations of the software and were quick to express their interest in taking part in the project. Potential new recruits immediately identified a wide range of ways they could see the software and its use making life easier for themselves and the people that they support.

### Parents & Carers' engagement

Interviews with parents and carers highlighted the key issues they hoped the project would address around need for improved information sharing and better advocacy for themselves and their children. They identified the need for information to be shared more efficiently between parents and carers and the various agencies for a more consistent and joined-up approach to planning and support. Parents & carers swiftly saw the potential of the multimedia advocacy approach to address these challenges. A foster parent shared expectation that 'it will be a useful tool for information sharing' and a mother said she hoped its use would 'ease transition to adult services and avoid mistakes by professionals.'

Parents shared the aspiration that use of WikiMe would help to capture the specific care needs of children and young people that use services so that parent & carers do not have to rehearse the same case history information repeatedly to different professionals. A mother interviewed explained, 'When you meet a healthcare professional you end up repeating yourself so many times, telling the same story over and over again'. She saw positive potential for the software to change this and declared that she was, 'excited to be able to share information about my child with other carers and professionals.' She hoped the pace and ease of use of new media tools could help change things, 'I just think technology is so quick and so easy and it's at your fingertips'.

Parents & carers identified the need for the individual, their communication and their wishes to be more effectively heard and understood so that their choices and aspirations would inform personalised and person-centred education, care and support. They wanted the voice of their children to be heard, as expressed by two parents at a project induction session, 'I am looking forward to giving my child a voice.' And 'I'm hoping it will give a better chance for my child to be understood.' A father said he saw the software could, 'help set goals, in terms of independence and work aspirations and make sure that he is central to the decision making.'

The direct recruitment of parents and carers of children and young people with disabilities has proved to be a slow process as those who might benefit most from the project's intended tools and methods are hard to reach, being short of free time and frequently isolated as a result of their challenging first-line care commitments. One professional shared this experience of recruitment, 'I have talked [...] to some parents about it who have heard of it, but they've said 'There's so much going on with my child at the moment I just can't cope with the idea of doing anything else'.'

## Professionals' engagement

Professional participants saw a direct fit for the project with the current ways care is expected to be delivered in line with the SEND Reforms. One service Manager recognised the alignment with SEND guidance, 'The code of practice says that information should be provided in the format that parents want' and a teacher saw the system's potential to provide, 'a more person-centred approach [...] multi agency person involvement [and] timely updating, shared by all.'

A significant number of professionals interviewed declared their positive aspirations for the project and had a strong grasp of its mission 'I got very excited about it. I thought it would be very fantastic. I understand it has to be held by the parent, so it's under their control, [...] they have to grant that access. I can definitely see it being beneficial.'

Other professionals were found not to be fully informed about the project and some who were asked to engage in the project were cautious about what the new practices entailed, the demands that participation would make on their time and the potential risks involved. On occasions, information on the pilot appears not to have been fully disseminated across professional teams. A parent commented 'Whenever I spoke to a professional and said 'Would you be interested in this?' They've just not heard of it. From a professional point of view they are just like 'I don't know what that is' - and they just shy away.'

Professionals also shared some confusion about their required role and input in the multimedia advocacy process and did not appear to have grasped the project's citizen advocacy goals 'I think we have [...] issues technically in terms of it has to be held by the parent as far as I'm aware, so we have to have a parent come to us and say can you go on it.' Such feedback suggested a need for the project to clarify the *active* role professionals might take e.g. in promoting its use with families as a tool to support their work, in requesting access to a wiki-me to add and view information

Similarly, there was caution about the equipment demands for professional participants, who simply require a computer with internet access to view shared content, but seemed unsure about this and saw the possible need to access camera or recording tools in their professional settings as prohibitive; '...another barrier for us is the ability to get on it. We have computers in our office but we don't have anything mobile or anything else or any other way to access things technically.'

Caution about data protection risk with the new ways of working required on the project were a significant factor in delaying engagement, particularly by healthcare teams and some schools. One professional shared this as the key obstacle to participation: 'It is literally the legalities of GDPR and the fear of information sharing that is holding people back.'

Project presentations and information resources affirmed that its products and methods are fully compliant with GDPR and that the project's approach effectively enshrines the spirit of citizen control of their own data that is behind GDPR regulation. However, this perceived obstacle was only removed once further endorsement from NHS/Local Authority information governance specialists had been provided. These engagement issues

contributed significantly to the slowing of professional recruitment and so the slippage to the project schedule overall.

A significant number of parents shared their frustration that poor engagement by professionals has stopped the project from gaining momentum as intended. One parent said, 'I kind of found that I was putting all of the stuff on and nobody was really looking at it, nobody really had time.' Another commented, 'I was really hoping that his school would have been on board by now, however they haven't even started training yet. Similarly, I would like his P.A. to actively engage with it.'

Some parents felt that professionals' caution reflected reluctance to engage in new, more 'parent-centred' ways, 'It's sort of a fear of information sharing. We need to just break through, (it's) just that they haven't heard of it. [...] Would they be prepared to log on so they can then view her documents? Possibly - a bit more training would be good!'

Some reflections shared by professionals suggested some of the working practises that they were finding it hard to 'break through' and adopt included new ways to of working together that challenged their professional principles on the safeguarding of vulnerable children and young people. New types of information bring new risks that require careful consideration and new standards of practise that need to be defined and applied, whatever the security of the software. One professional explained, 'When you said it's password-protected and the parent has requested they've 'lost their physical copy, please can you send me one'. In theory I see no issue with that - but it turns my stomach over! [...] Confidentiality is drummed into you when you first do your training, it's like 'Don't share anything with anybody unless you think a child's life is in danger!' '

Notwithstanding the challenges faced however, there were clear testimonies from professionals at focus groups that their engagement had been achieved, despite preliminary caution. A healthcare professional explained, 'Initially everyone was like 'Oh no we can't do this!' but now it's the norm.'

Participants saw solutions to engagement barriers could be achieved principally through more training provision for parents and professionals alike, but the time implications for this were cited as a possible further challenge for take-up. Although several participants emphasised how easy the software was to use, they were clear that they felt training could improve retention, that 'people would be more likely to stay on board' with additional practical training to address their insecurities with the system. They were concerned that those professionals they had invited to engage with the system 'didn't have a clue how to do it' and wanted more training for professionals to access the software. They were frustrated that it took professionals long periods of time to engage and respond, but again acknowledged that they 'haven't got the most time in the world either!'

Parents did see the potential of their applying a peer learning and support approach, so that new parents setting up a wiki could be allocated, 'a Buddy - a parent who has already kind of gone through it and really understands' to support them. Similarly, they proposed face to face peer-support sessions, 'like a drop in - a wiki drop in. Come around, share the Wikis, talk about the Wikis [WikiMe]. Something like that'.

Parents and professionals' experiences and attitudes to engagement were varied and their feedback on factors affecting adoption have provided valuable insights to help inform scaled adoption as the project progresses. These are summarised in the 'Recommendations' section at the end of the Report.

Whatever the challenges of engagement experienced on the pilot, steady growth in take-up of the Software and its multimedia advocacy approach is evidenced from the data provided from software analytics. This data also highlights the benefits of recruiting at organisation level and recruiting via professional channels as well as directly engaging parents and carers. Setting up new participants via organisations, especially through schools, produced surges in the numbers of new individual accounts at start of the school's term, as class groups got on board. This route provided prospect for parents and teachers taking up multimedia advocacy together alongside the child, supporting each other with the challenges around adoption and directly seeing the tool's information sharing potential as data showed parents and professionals increasingly engaged in exchanges around the child. A parent described this aspiration at a joint induction session with professionals, 'We will use the diary every single day - it's got subsections [...] and the school is on board with completing that and then I complete my element, or the family do.'

## 2. Impacts - for communication, self-advocacy and personalisation

The following section presents an account of how the software and approach worked in practice and provides testimony on the impacts evidenced on the quality of **communication, self-advocacy** and **personalisation** of children and young peoples' education, health and care provision.

Parents taking part in the pilot repeatedly cited improvement in the **Communication** around the child or young person as a result of participation in the Pilot. They shared immediate benefits, simply achieved by opening up the new multimedia channels afforded by the software, for example across the home/school divide; 'Between school and myself and the family, it allows school to sort of say 'I've seen it' in an informal way, but also family members to go 'Oh wow, that's amazing!'. Valued

The key communication benefit shared was the way it connected together the different zones of the child or young person's life and the linked the various supporters together. A parent described how, 'The WikiMe is just a tool, but it pulls everything into one place and people are becoming more comfortable using it.' A parent stated it was 'Brilliant for carer training. Brilliant for sharing info.' and 'Brilliant for communication between college and family.' Another Parent found the tools invaluable for sharing their child's experience of overnight or 'respite' care. Testimonies demonstrated the numerous settings and agencies that often worked with one individual and highlighted that parents otherwise lacked a detailed picture of their own child's experiences. The system also worked the other way, allowing parents to share aspects of their child's life that other carers, therapists and clinicians would not be able to access. A foster parent explained, 'Others can see the

different areas of our child's life that they don't ordinarily see.' Providing a fuller account of the individual and a more holistic view of their life.

The benefits of the WikiMe's support network were seen to be practical as well as emotional. 'It can reassure people that care for him of different aspects of his care - such as how to put his splint on, feeds, how to hoist his chair into the car etc.' Parents described the benefits of sharing reports and evidence of progress they have made that might otherwise not be believed. The Wiki component of the toolkit provides a place to store and organise instructional information, as one parent explained, 'We're on our way to developing a great resource and a user manual for his support.'

A multimedia account of the child or young person's daily life also afforded opportunity for parents to review, observe and reflect upon how they were being supported, a process often hard to achieve in the hurly burly of family life. A parent described that she regularly used the media content to review what her child had done on past overnight visits, that she'd show people 'look what a wonderful time she had!' Similarly, a foster carer used a tab at the foot of the screen to document details she had learned about the child using the software to record details on, 'how she communicates, what she likes, what her preferences are, things I need for us to discuss and work out together, and remembering to send stuff for next time - that kind of thing.'

The pilot has already evidenced remarkable examples of the system clearly facilitating improved communication across circles of care and support and in the process both empowering and reassuring parents through provision of new channels for the sharing of information in rich media formats.

The **self-advocacy** of the individual children and young people has also been enhanced through the use of the software and parents shared that use of the system 'informs others of our child's needs, wishes, strengths and challenges'. Self-advocacy starts with 'knowledge of self' and a personal multimedia profile provides a valuable tool for the individual to use to build such a picture. A parent described that over time it created a 'life story' for their child, with which to 'look back on achievements, where he was before, and where he is now.' Use of the software was described as 'a long term venture' for the individual that would 'record useful events in his life' and so prove useful for him as an adult.

Critically, the accessibility of the software and its use of multimedia immediately engaged young people and those more able could populate the content themselves or with minimal support. Children using WikiMe affirmed their view that all of the tools were 'easy to use'. A parent explained that her daughter could effectively communicate using the tool, 'she can add things, she can look at things' and that this had a powerful effect as her daughter gained real agency in 'making sure that everybody involved in her life is working towards the same place'.

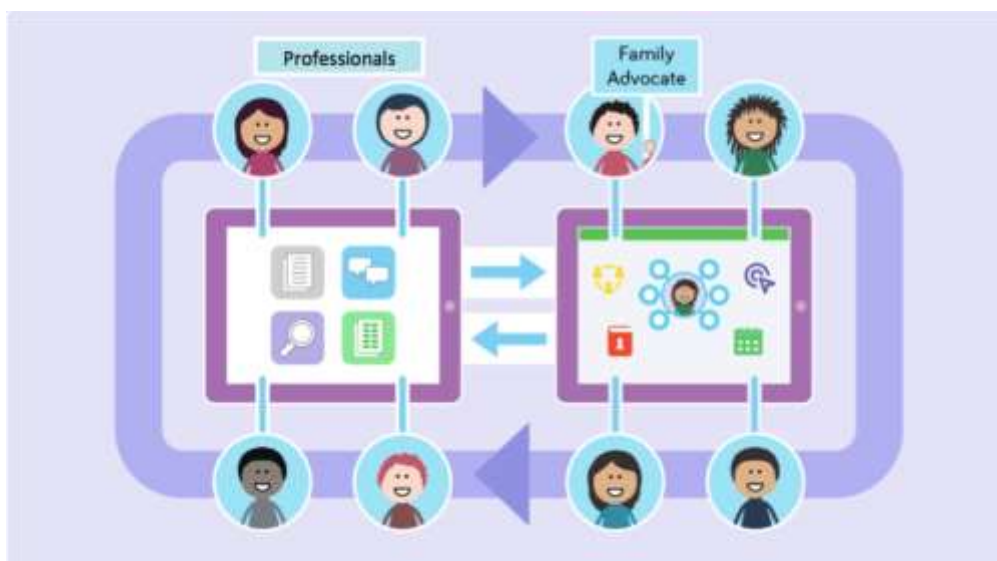
The evaluation provided evidence that a more **personalised** and person-centred model of education, health and care is potentially enabled with the multimedia advocacy tools and approach. Several parents flagged the value they saw for the tool as their child approach transitions in their lives; between schools, from school to college, for the move to adult life

in the community. One explained how she had worked with the tool around her child's aspirations, 'I do all the goals, cross referenced to the Education, Health and Care Plan, so if it's on there, then you'll see the goal being achieved.' At the same time it provides 'so much more than just a sort of official record' as another carer explained, 'I take great pride in that because I can see what I have achieved and I love looking back through at what she's done and how happy she's been.'

The clearest view of the successes achieved on the pilot has been provided by parents who provided case studies of the intended impacts for their children. One mother affirmed, 'It's been fantastic, my child has much more holistic care and support - **and life** through having WikiMe.' Another provided a rallying call to parents and professional with this quotation at the end of her interview;

'You've got to use it because technology is the way forward, it really is, and communication is key [...] you can look back on that video time and time again I think that there are so many uses to this, not just communication. There are **so many uses** that it just saves time, energy, everything - and it's all in one place. So it's just brilliant!'

### 3. Interim analysis and conclusions



Multimedia advocacy requires engagement and active participation from all key stakeholders to fully realise its capability to facilitate co-production of person-centred education, health and care. The project has already evidenced benefits for individuals, parents, carers and professionals, but it also highlighted barriers to adoption.

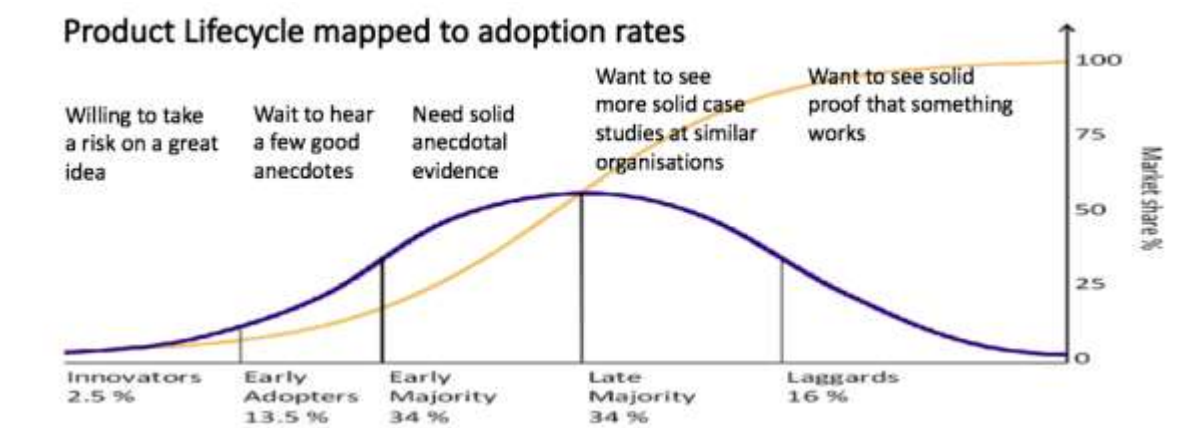
These have principally centred on the less than complete take-up of the implementation across education, health and care agencies. A range of different factors have been identified as influencing professionals' ability to work in the new ways that the WikiMe system demands and these are described above.



The pilot phase of the implementation has identified strong factors that will encourage parents, teachers and personal assistants and carers are to take part and use these new approaches.

The slow take-up, principally by professionals, has highlighted the innovation that this intervention represents and thus the challenges posed around cultural change for professional practice. Despite the recommendation and official affirmation of the potential value of use of technology for health and care of citizens with support needs, the reality faced across many scenarios where digital tools are being implemented is that take-up of these new ways of working faces obstacles and is slow.

The first phase of the implementation in Herefordshire has usefully identified the key factors and it is useful to step back and consider a broader understanding of how people typically respond to the challenges associated with taking up innovation. Such behaviours have been considered in the context of organisations and consumers and their response to innovative products and findings have been mapped to a representative 'lifecycle' diagram that may be useful to consider as we chart the next phases of this implementation.



It is important to recognise the marketing and communications effort, as well as staff resource levels that are needed to achieve the willingness of various participating stakeholders to take part in new ways of working and the cultural change that such innovations genuinely demand. The hesitancy that the project has hitherto encountered can be counteracted with the sharing of testimonies, such as those featured in this report, from the 'innovators' and 'early adopters' who have pioneered use of WikiMe in the first phase of the project. Alongside improved provision of information, these accounts dispel fears by providing credible evidence of the potential benefits. If accompanied by endorsement from leaders as well as peers, this will help persuade our 'late majority adopters', who want to see evidence and proof, that this new approach is worthy of their investment of time and expertise.

#### 4. Interim recommendations

The evaluation and subsequent reflection by participants and the project team have identified several strategies that can help to address these recruitment and engagement challenges in the next phase of the project. These have centred on developing stronger communications targeted at each stakeholder group, improving training and tailoring this more precisely to professionals and parents & carers respectively, alongside face to face sessions that brings all stakeholders together. Additionally, reflective analysis of the issues raised by professional participants has highlighted a broad need for the development of simple, clear standards and protocols for effective multimedia advocacy practise to help allay fears around the innovative change to communications that the multimedia advocacy approach facilitates.

The interim evaluation has prompted the following practical recommendations from participants working :

### **1. Dissemination of the project and its goals**

- Develop and enhance the provision of information to professionals and organisations about the multimedia advocacy implementation project, it's mission and scope
- Promote the positive impacts for disabled children and young people, their families and carers
- Provide authoritative information and guidance to address the specific obstacles and anxieties expressed by parents and professionals identified on the project

### **2. Recruitment**

- Undertake pro-active marketing of the project to each stakeholder segment at all levels to strengthen recruitment and achieve system-wide adoption
- Provide clear messaging to all stakeholders required to engage with a clear explanation why, endorsed by Directors and Managers of all relevant services

### **3. Practical guidance and standards**

- Clarify the principles of WikiMe ownership and control by individuals with disabilities and their immediate advocates, typically parents, carers or key-workers
- Explain the product's adherence to Data Protection regulation and promote better understanding of GDPR regulations and principles and how these map to the project's citizen advocacy focus.
- Provide best practise models on how to use the tools to enable collaboration between parents, carers and professionals and to foreground the wishes, needs, choices and aspirations of children and young people with disabilities and SEN

### **4. Training**

- Provide professionals with targeted and accredited training to cover the issues above with clear guidance on best practise for these new ways of working
- Put mechanisms in place to enable peer training for disabled children and young people, parents & carers and education, health and care professionals