Evaluation Report: Care Profiles

Questionnaire on Family Experience and Perceived Impact

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Executive Summary

Introduction

This report presents findings from an evaluation of the A Little About Me (ALAM) care profile, a digital tool designed to support children and families in preparing for healthcare interactions. The evaluation focuses on family perceptions of usability, communication, involvement in care, preparedness, emotional experience, and overall value. The aim is to inform how the care profile is designed, implemented, and integrated within care pathways, with a focus on supporting family-centred care and more responsive healthcare delivery.

Methods

A cross-sectional questionnaire was conducted with families who completed a care profile prior to a hospital visit. Recruitment took place via an in-app intercept at the point of profile generation. A total of 41 caregivers completed the questionnaire. Quantitative data were analysed descriptively using percentage agreement, and qualitative responses were used to contextualise findings. The results provide early, self-reported evidence and should be interpreted as directional rather than generalisable.

Results

Findings show a consistent pattern of positive experience across key domains.

- **Usability and completion experience**: The care profile was widely perceived as easy to complete. However, around 20% of users did not recognise that they had completed a profile, indicating a gap between usability and comprehension.
- **Family involvement in care**: 95% of respondents reported feeling more involved in their child's care, 90% felt more confident advocating for their child, and 85% felt like a partner in care.
- **Communication and personalisation**: 93% agreed the profile made it easier for their child to communicate what matters to them. Families also reported that it helped reflect their child's needs, preferences, and personality, suggesting strong perceived relevance.
- **Preparedness and emotional experience**: Families reported improved preparedness, better anticipation of needs, and reduced anxiety ahead of hospital visits. The profile supported reflection and parent-child discussion prior to care.

- **Perceived value and recommendation**: Perceived value was high, with 85% agreeing the profile added meaningful value, 100% agreeing it was worthwhile, and 100% willing to recommend it. The Net Promoter Score was 73.
- **Early signals of downstream impact**: While 95% believed the profile could contribute to better care outcomes, reported downstream effects were more moderate, with 78% reporting easier attendance and 76% improved sentiment towards future visits.
- **Opportunities for improvement**: The main improvement area identified was around sharing and access. Particularly about reducing reliance on printing care profile reports, which creates friction in real-world use.

Discussion & Recommendations

The findings suggest that the care profile is experienced as a low-friction, relevant tool that supports communication, participation, and preparedness ahead of healthcare interactions. The strongest findings relate to expression of needs, family involvement, and emotional readiness.

There is a consistent pattern in which perceived value is high, while effects further downstream may be present but less strongly endorsed. This is consistent with early-stage implementation, where changes in understanding and preparation precede sustained behavioural or system-level outcomes.

Two priority areas for refinement emerge:

- Improve completion clarity so users better understand what has been created and how it should be used
- Strengthen sharing and integration into care workflows to ensure the information is accessible and usable in practice.

Conclusion

This evaluation provides early evidence that the ALAM care profile is perceived by families as a useful, low-friction tool that supports communication, participation, and preparedness ahead of healthcare interactions. The findings are consistent and credible for an early-stage evaluation but remain based on self-reported data from a small, self-selected sample. While encouraging, the findings remain early and should be interpreted cautiously. Care profiles appear to support key parts of the care journey, particularly preparation, communication, and family involvement, but further work is required to determine whether these effects translate into consistent changes in clinical practice and longer-term outcomes.

Introduction

Paediatric care is influenced by whether children and families feel informed, prepared, and able to communicate their needs. Patient-centred care is widely recognised as a core dimension of healthcare quality, with communication, emotional support, and responsiveness identified as key components of effective care (Institute of Medicine, 2001). In paediatrics, this extends to patient- and family-centred care, which emphasises partnership with families, recognition of their role in supporting the child, and the importance of involving both children and caregivers in care processes (American Academy of Pediatrics, 2012).

This is particularly relevant in hospital settings, where children and families often experience uncertainty, stress, and difficulty communicating preferences or support needs. Evidence suggests that family-centred communication and partnership can improve experience, support safer care, and enable more responsive interactions (Khan et al., 2024). For families navigating additional or context-specific needs, the ability to share individualised information clearly and in advance may be especially important. This aligns with broader literature describing family-centred care as a model that supports alignment between care delivery and the needs, values, and circumstances of children and families (Kuo et al., 2012).

The A Little About Me (ALAM) care profile was developed in response to this need. It provides a structured way for families and children to share information about what matters to them, including preferences, triggers, and support needs that may influence care. A tool like this is not intended to change clinical care directly, but intends to support circumstances around care, such as preparation, communication, and participation.

This evaluation assesses how families experience care profiles in practice. It focuses on perceived usability, communication, involvement in care, preparedness, emotional experience, and overall value. The aim is to provide an early assessment of whether the care profile supports key preparatory and communicative aspects of the care journey, and to identify implications for further development, implementation, and evaluation.

Aims & Objectives

The purpose of this evaluation was to assess family perceptions of care profiles and to understand whether it supports key aspects of the care journey that matter to families and to care delivery.

The work examined how completing the care profile affects preparedness, confidence, and sense of involvement in a child's care; in what ways it may support personalised, coordinated, and timely care; whether families feel more supported through its use; and which aspects of the care profile work well or require improvement. The intended use of the findings was to inform how the care profile is designed, implemented, and integrated, and to guide refinement in ways that support meaningful reasonable adjustments, communication, and trust between families and staff.

Specifically, the evaluation sought to:

- Assess the perceived usability and experience of completing the care profile
- Understand its impact on family involvement, confidence, and role in care
- Explore perceived effects on communication and the ability to express needs
- Examine its influence on emotional experience and preparedness for hospital visits
- Identify perceived value and opportunities for improvement

Methods

Study Design

A cross-sectional evaluation design was employed using an online questionnaire to capture family's perceptions of care profiles. Questionnaire items were informed by the Theory of Change framework and designed to assess family-reported experience across domains relevant to the intended function of the care profile, including family involvement in care, communication, preparedness for visits, emotional experience, perceived value, and opportunities for improvement.

Participants and Recruitment

Participants were families who had completed a care profile. Recruitment was conducted through an in-app intercept presented at the point of care profile generation. Families who consented were redirected to complete a short questionnaire.

The final analytic sample was 41 families. Some users were screened out during recruitment, including those who did not recall completing a care profile and those who did not consent to participation.

This recruitment approach enabled feedback to be captured close to the point of use but also introduces the likelihood that the sample over-represents families who were able and willing to engage with the digital process and saw valuing in completing it.

Participation was voluntary, and respondents completed the questionnaire anonymously.

Data Collection

Data were collected via an online questionnaire. The questionnaire included a combination of Likert-scale items and open-text questions to allow both quantitative assessment of perceived impact and qualitative exploration of implementation experiences and improvement opportunities. The questionnaire captured demographic information and assessed perceived impact across usability, communication, involvement, preparedness, and value. Likert-scale items used a 5-point agreement scale ranging from *strongly disagree* to *strongly agree*.

Open-text questions were included to explore perceived barriers and enablers to use, opportunities for improvement, and contextual factors influencing adoption and sustainability.

Data Analysis

Quantitative data were analysed descriptively. Frequencies, percentages, and mean agreement scores were calculated for Likert-scale items. Given the relatively small sample size and the exploratory nature of the evaluation, no inferential statistical analyses were conducted. Percentage agreement (defined as the proportion of respondents selecting *agree* or *strongly agree*) was used as the primary indicator of perceived positive impact across domains.

Qualitative data from open-text responses were analysed using a thematic approach. Responses were reviewed iteratively to identify recurring patterns and themes relating to barriers, enablers, implementation experiences, and perceived value. Illustrative quotes were selected to exemplify key themes and to provide contextual depth to the quantitative findings.

Quantitative and qualitative findings were integrated at the interpretation stage to provide a richer understanding of how and why perceived impacts occurred, and to support triangulation across data sources.

Results

Sample Characteristics

A total of 41 families completed the questionnaire. The sample included families across a range of child ages and care contexts, including children with additional needs. The distribution of male and female children was evenly split.

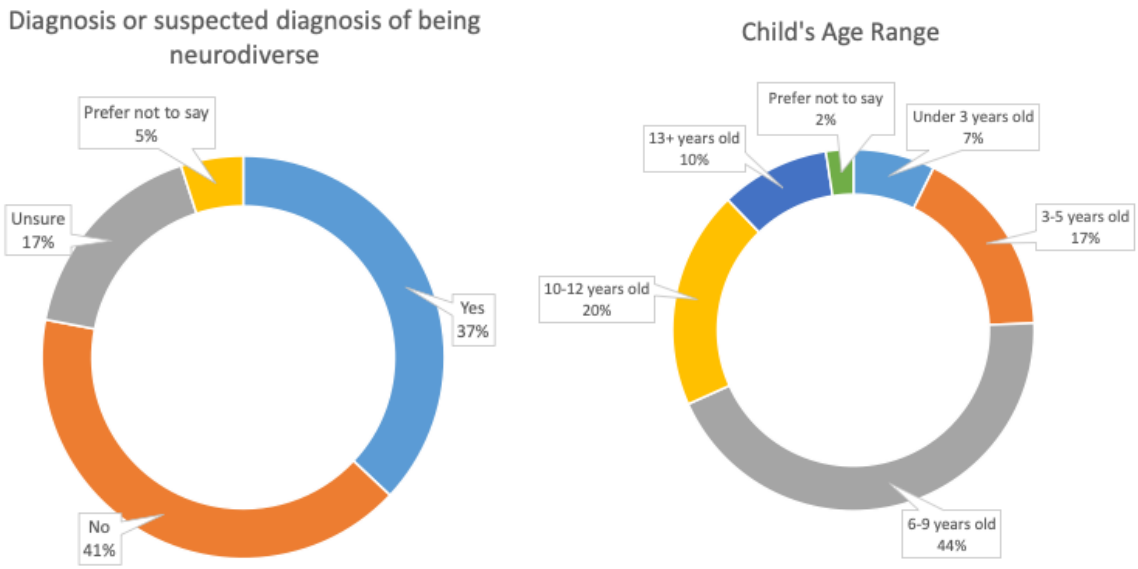

Figure 1. Same characteristics: neurodiversity status (left), child age distribution (right)

This breadth is useful, but the sample remains relatively small and context specific. The findings therefore provide early, directional evidence across a varied family sample, rather than statistically generalisable estimates of impact.

Questionnaire Key Findings

Findings indicate a consistently positive pattern across multiple domains of family experience. High levels of agreement were observed across communication, family involvement, and perceived value, with many measures exceeding 90% agreement. This pattern suggests a coherent experience across the care profile journey. The following sections outline the results from the questionnaire.

Perceived Usability and Completion Experience

Families reported low perceived friction when using the care profile. Overall, responses suggest that the care profile was experienced as straightforward to complete and easy to understand. Qualitative feedback reinforces this, with one caregiver describing it as *"[Liked that it was] easy to use and involved child."*

This is important because perceived usability is a prerequisite for broader value and impact on behaviour. If the feature had been experienced as burdensome or confusing, it would be much harder to interpret the more positive findings in other domains as meaningful. Instead, the data suggest that the care profile is accessible enough to support participation by families, including parent–child involvement in some cases.

However, during recruitment and screening, a subset of users (~20%) progressed through the flow without recognising that they had completed a care profile (Figure 1). This suggests a gap between interaction-level usability and journey-level comprehension. In other words, families may be able to complete the immediate task with ease while still not fully recognising what has been created or why it matters.

This distinction is important because families may be able to complete the steps without fully understanding what they have created or how to use it. This suggests that the experience is operationally easy, but that the meaning and outcome of the journey could be made more explicit. This highlights a potential design learning around stronger signposting and clearer completion feedback.

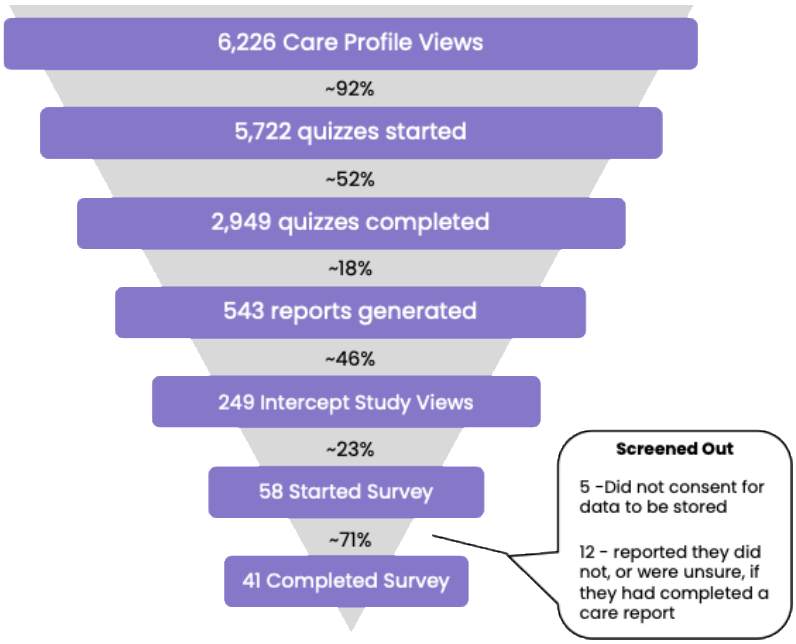

Figure 2. End-to-End Care Profile Funnel from Access to Questionnaire Completion

Family Involvement in Care

One of the strongest findings in the dataset is the perceived effect of the care profile on families' role in care. Ninety-five percent of respondents reported feeling more involved in their child's care, 90% felt more confident advocating for their child and asking for support, and 85% reported feeling like a partner in their child's care.

Qualitative feedback helps explain why these findings are so strong. One caregiver noted that they "*[Liked that] both child and parent can partake in the process*." This suggests that the care profile may be creating a structured opportunity for families to enter the care process more actively as partners in care.

These results suggest that families perceived the care profile as supporting a more participatory role, enabling parent and child to feel more explicitly engaged in expressing needs and contributing to care conversations. This interpretation is consistent with family-centred care principles.

That said, the strength of these findings should be interpreted carefully. The questionnaire measures perceived involvement, confidence, and partnership, not directly observed behaviour in clinical settings.

Communication, Child Voice, and Personalisation

There were also clear communication benefits from the questionnaire findings. Ninety-three percent of respondents agreed that the care profile made it easier for their child to communicate what matters to them, and 83% agreed that it made it easier to navigate healthcare services.

Qualitative responses provide important context for these figures. Families described the profile as creating an "*Opportunity to talk about what support son would need and how best to help him with prompts,*" and as helping children feel "*part of the conversation and process*." These responses suggest that, in part, some of the value of the care profile comes from the structured conversation it enables between caregivers and child before care takes place.

This is especially important in paediatric care as communication is often relational and preparatory. The care profile appears to function as a scaffolding tool that helps families organise, express, and share individual context in a way that may otherwise be difficult in stressful or time-limited situations. This seems particularly relevant where children have additional, sensory, or nuanced needs that might make routine interactions more difficult or stressful.

The findings also point toward a potential personalisation function. 98% of families reported that the care profiles helped reflect their child's personality, triggers, and support needs, 98% also agreed it helped share what matters most about their child, and 85% agreed the care profiles reflected their family values and preferences. Families reported appreciating "*Everything. The fact you want to know about the child*". As well as valuing "*That there were options for sensory needs and understanding the needs of my child*". This suggests that care profiles enable a structured mechanism for sharing individualised information that families perceive as relevant to care.

Preparedness & Emotional Experience

Families reported that completing the care profile improved their sense of preparedness for hospital visits, with strong and consistent agreement across multiple dimensions of preparation. Eighty-five percent agreed it improved how their family prepares for visits, 83% said it helped anticipate challenges or needs, 98% said it helped them think through their child's needs during the visit, and 90% said it made the hospital visit feel more manageable. Qualitative feedback was also consistent in describing emotional benefits, with caregivers reporting that their child felt "*more relaxed*," "*calmer, and less anxious*," and that the profile "*helps reduce the worry for both child and parent so we can speak about the hospital visit together*."

These findings suggest a potential mechanism underpinning the preparedness effect. The care profile appears to support preparation by structuring information, but also by prompting reflection and conversation before the visit. The high agreement around thinking through the child's needs suggests that families are engaging in more deliberate, anticipatory planning, rather than reacting in the moment. At the same time, the qualitative feedback suggests that this process also reduces uncertainty and emotional burden, enabling families to approach the visit with greater clarity and control.

This is relevant in the context of paediatric care, where anxiety, uncertainty, and perceived lack of control can shape both parent and child experience. The consistency and strength of these responses suggest that the care profile may help families feel more ready for what is ahead, both practically and emotionally. However, these findings are based on self-reported, immediate perceptions. They support the conclusion that families felt more prepared and less worried, but do not establish whether these effects persist over time or translate into observable differences during the hospital visit itself.

Perceived Value and Recommendation

Perceived value was high across the sample. Eighty-five percent of families agreed that the care profile added meaningful value to their hospital experience, and 100% agreed that it was worthwhile for families like theirs. This high perceived value was reflected in recommendation, with 100% saying they would recommend the care profile to other families and an NPS of 73, driven by a high concentration of 10 out of 10 scores and only two detractors.

Qualitative feedback helps explain this pattern. Families described the profile as "*a fantastic tool,*" "*helpful in preparing my daughter for surgery*," and useful because it "*asked about little things that we didn't even think about*." Others emphasised its

relevance for individual family circumstances, including additional needs, and its value in helping both parent and child prepare together.

Taken together, these findings suggest that families did not seem to experience the care profile as an additional task but identified it as a meaningful and relevant part of the care journey. Recommendation also provides an additional indicator of perceived value beyond satisfaction ratings alone; it suggests that respondents valued the profile for themselves as well as considered it worthwhile to consider recommending to others.

At the same time, this should be interpreted cautiously. As the sample was recruited following profile completion, the findings are likely representative of respondents who saw value in completion of the care profiles, rather than a direct indication of likely endorsement across the wider population.

Early Signals of Downstream Impact

The findings suggest that families perceive the care profile as having the potential to influence outcomes beyond the point of completion, although these effects appear to vary. Ninety-five percent of respondents believed the care profile can contribute to better care outcomes, indicating strong confidence in its overall value. In contrast, reported downstream indicators were more moderate: 78% agreed it makes it easier for their child to attend hospital appointments, and 76% said it positively influenced how their child feels about future appointments.

This is consistent with early-stage implementation, where early impacts such as communication, and confidence tend to emerge more strongly and immediately than behavioural or longer-term outcomes. However, it does suggest that families see potential for the care profile to support later points in the care journey, including appointment attendance and future visit sentiment. The results therefore provide encouraging early results and indicate that outcomes such as attendance and future visit sentiment should be captured in future evaluations to assess whether these effects are sustained and observable at scale.

Opportunities for Improvement

The clearest opportunity for improvement identified by families related to sharing and access. One caregiver commented: "*It would be good if this could be shared directly rather than having to be printed as it's another thing to remember*."

This is an important finding because it suggests that families did not report dissatisfaction with the idea or content of the profile. Instead, the issue comes from the point where the output needs to be carried forward and used in practice.

This is an important finding for implementation. If a tool is valued but difficult to share, its real-world impact may be limited by delivery processes rather than by lack of demand or acceptability. The evidence therefore suggests a workflow and integration gap: the care profile appears to be experienced positively by families, but its practical utility may be reduced where digital sharing to care providers is limited, and printing becomes an additional burden.

Discussion

This evaluation provides early evidence that the ALAM care profile is perceived by families as a low-friction and relevant tool that supports participation, communication, and preparedness in advance of healthcare interactions. This pattern is consistent with wider literature showing that patient- and family-centred care in paediatrics is most often valuable when it strengthens the conditions around care, particularly information sharing, partnership, and responsiveness to family needs, rather than acting as a direct intervention on downstream clinical outcomes (Institute of Medicine, 2001; American Academy of Pediatrics, 2012; Kuo et al., 2012). In that sense, the care profile appears to act primarily as upstream support ahead of the care appointment.

The most consistent findings in the evaluation relate to perceived usability, family involvement, and communication. Families reported that the care profile was easy to complete and that it supported parent and child participation. At the same time, some users did not recognise that they had completed a profile, indicating that ease of interaction does not necessarily translate into full comprehension of the journey outcome. This distinction is important because it suggests that successful task completion alone is not sufficient if the purpose and output of the tool are not clear. From an implementation perspective, this aligns with broader evidence that the effectiveness of patient- and family-centred tools depends not only on acceptability, but also on whether their purpose is visible and meaningful to users within the care journey (Kuo et al., 2012).

Findings relating to family role in care suggest that the care profile may support a more participatory experience of care. Families reported feeling more involved, more confident advocating for their child, and more like partners in care. This is consistent with established definitions of patient- and family-centred care in paediatrics, which emphasise the family as the child's primary source of support, and position children and families as integral partners in decision-making and care processes (American Academy of Pediatrics, 2012). However, these findings should be interpreted carefully. This study captures perceived changes in involvement and confidence, not directly observed changes in behaviour or clinical interaction.

The communication findings further support this interpretation. Families reported that care profiles made it easier for children to express what matters to them and supported conversations about support needs prior to hospital visits. This suggests that care profiles may function as a structured communication aid, helping families organise and communicate relevant contextual information in advance. That interpretation is consistent with evidence from paediatric inpatient settings showing that more structured family-centred communication can improve family experience and communication processes, while also enabling families to contribute information that might otherwise be missed (Khan et al., 2018).

Improvements in preparedness and emotional experience are also consistent with this interpretation. Families described feeling more prepared, and qualitative feedback suggested reduced anxiety and more productive parent-child conversations before visits. This aligns with the wider paediatric literature, where preparation, communication, and family involvement are consistently recognised as important for reducing uncertainty and supporting a better experience of care (Institute of Medicine, 2001; American Academy of Pediatrics, 2012). Taken together, these findings suggest that the care profile may add value during the anticipatory phase of care, when families are trying to understand, prepare for, and emotionally manage an upcoming healthcare interaction.

There was also a consistent pattern when comparing downstream indicators. Belief in the value of the care profile was high, while reported effects on outcomes further along the care journey, such as ease of attending appointments or improved future sentiment, were positive but more moderate. This aligns with early-stage evaluations of service tools, where early indicators, such as usefulness, confidence, communication, and preparedness appear before behavioural or system-level effects can be observed. This is also consistent with broader family-centred care literature, which suggests that partnership and communication are foundational mechanisms, but that translation into routine practice depends heavily on implementation quality and system context (Kuo et al., 2012).

Perceived value was reinforced by high levels of recommendation. Families reported strong willingness to recommend the care profile to others, suggesting that it was experienced as relevant and worthwhile within the sample. However, as participants were recruited after completing the profile, these findings reflect the views of those who chose to engage, as well as those who likely saw the value in completing the care profile, and may not represent all families.

The primary improvement identified by families related to how the care profile is shared and used in practice. Friction associated with printing and limited digital sharing suggests that the care profile may not consistently reach or be used by staff in practice. This is an important implementation finding. Family-centred care depends on whether information is accessible, visible, and actionable within real clinical workflows (American Academy of Pediatrics, 2012; Kuo et al., 2012). Therefore, the current findings suggest that the next challenge is ensuring care profile information reaches staff in a format and at a time that allows it to be used in practice.

Taken together, the findings suggest care profiles may function as a valuable upstream support for participation, communication, and preparation. While the evidence remains early-stage and self-reported, the consistency of findings across different themes provides a credible basis for further refinement and evaluation. A key next step is to assess whether clearer completion feedback, better sharing pathways, and stronger integration into care processes allow that perceived value to translate into more consistent practical use.

Limitations

This evaluation provides early, practice-relevant insight into family experience of care profiles; however, some limitations should be considered when interpreting the findings.

First, the evaluation is based on self-reported data collected shortly after profile completion. Findings therefore reflect perceived experience rather than independently observed behaviour or outcomes. This is appropriate for assessing perceived usability, communication, and preparedness, but it limits conclusions about actual changes in care delivery, clinical interactions, or longer-term outcomes.

Second, the sample size was relatively small and was not intended to be statistically representative. Although the sample included a range of family contexts, the findings should be interpreted as directional rather than generalisable. Recruitment through an in-app intercept is also likely to have favoured families who were willing and able to engage with the digital process, introducing potential self-selection bias.

Third, the evaluation captured experience at a single point in time, shortly after completion of the care profile. It therefore provides limited insight into whether perceived benefits persist during or after the healthcare interaction.

Taken together, these limitations mean the findings are best understood as early real-world evidence of family perception and experience, rather than as definitive evidence of impact on practice or outcomes.

Implications for Practice

The findings suggest that the care profile is likely to add value as a preparatory tool. Introducing it early enough before appointments to allow reflection, discussion, and planning may be beneficial.

The results also indicate that completion is not the same as comprehension. Families may complete the journey successfully without fully recognising what has been created or how it should be used. In practice, this means the completion point should communicate more clearly what the output is, why it matters, and what families should do next.

A further implication is that the care profile must be easy for clinical teams to access and use. For the profile to influence care interactions, the information captured needs to reach staff in a format and at a time that supports practical use. Additionally, reliance on families bringing the care profile themselves introduces friction and may reduce the likelihood that the profile is used consistently in practice. More seamless digital sharing is important for translating positive family experience into practical value.

Overall, the main implication for practice is that the care profile should be implemented as part of a broader pathway for preparation, communication, and use in care.

Recommendations & Next Steps

The findings suggest a focused set of priorities for refinement and further evaluation.

First, improve completion clarity within the user journey. Some families completed the process without fully recognising that they had created a care profile or understanding what it was for. The completion point should therefore communicate more clearly what has been generated, why it matters, and what families should do next.

Second, strengthen profile sharing and workflow integration. The main practical friction identified by families relates to access and reliance on printing. Priority should be given to improving how care profiles are shared, accessed, and carried forward into care interactions so that information provided by families can be used more consistently in practice.

Finally, strengthen future evaluation by assessing impact within practice. Current findings provide early evidence of perceived value, especially for communication, preparedness, and family involvement ahead of a care appointment. The next phase

of evaluation should assess whether these reported benefits influence the appointment itself, whether profiles are used by staff, and associated with changes in family or appointment experience.

Conclusion

This evaluation provides early, real-world evidence that the ALAM care profile is perceived by families as a useful and low-friction tool that supports communication, participation, and preparedness ahead of healthcare interactions. The strongest findings relate to improved expressing of needs, increased confidence and involvement in care, and reduced anxiety through structured preparation. While there are encouraging early finding that these benefits may extend to the appointment experience, these remain self-reported and require further validation. Importantly, the findings also highlight that impact is reliant on implementation, particularly around clear journey feedback and effective sharing into clinical workflows. Overall, the evidence supports a cautious but positive interpretation: the care profile appears to help families prepare for care and communicate their needs more clearly, with further work needed to confirm how this translates into practice and outcomes.

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