National Clinical Programme
for Eating Disorders

PiLaR Programme - An Evaluation

National Clinical Programme for Eating Disorders

PiLaR Programme
Supporting Families: Combining education, experience, skills and support

What have we learned?

BODYWHYS
The Eating Disorders Association of Ireland

UCD DUBLIN
University College Dublin
Ireland's Global University

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Eating Disorder Services

EVALUATION OF THE PILAR PROGRAMME

FOREWORD

On behalf of the HSE National Clinical Programme for Eating Disorders, I am delighted to introduce this evaluation of the PiLaR (Peer-Led–Resilience) Programme by Bodywhys, which has been undertaken by the Department of Child Psychiatry in UCD.

In its role as the National Eating Disorder Association of Ireland, Bodywhys has been a tireless supporter of people with eating disorders and their families since 1995. As our partner service user organisation in developing the HSE National Clinical Programme for Eating Disorders (NCP-ED) we have witnessed their dedication at first hand in our work together on the HSE Model of Care.

The PiLaR programme is a strong example of an accessible programme that provides support and psychoeducation for carers struggling to support their unwell loved one. That over 600 family members have to date attended PiLaR groups across the country demonstrates that word is spreading about how valuable it can be for family members of people with eating disorders.

As part of our joint commitment to service quality in the NCP-ED with Bodywhys, we want to explore and understand the impact of PiLaR through a cycle of continuous quality improvement. This evaluation is the first step and indicate that PiLaR has an important role to play in enhancing carer understanding, providing support and meeting expectations.

I would like to congratulate Bodywhys, Harriet and Kathy, as well as to thank Professor Fiona McNicholas and Dr Ingrid Holme (UCD) for their work, as well as all of those who participated. We look forward to learning from their insights and feedback.

Dr Sara McDevitt
HSE National Clinical Lead for Eating Disorders
February 2019

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We are immensely grateful to the supporters who gave their time and shared their experiences during the informal interviews.

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1. INTRODUCTION

Eating disorders (ED) affect up to 5% of the population and anorexia nervosa has the highest mortality rate of all mental health conditions[1]. Eating disorders can impact negatively on every aspect of the person's life including their relationships and interactions with their family and friends. Family and friends can provide valuable support towards recovery from eating disorders, and there are increasing calls for them to be included in treatment plans, especially when the person is under 18 or living with their family. However, supporters can find themselves left alone and ill-equipped to manage distressing psychosocial situations[2]. Indeed, research indicates that carers of patients with eating disorder experience a higher negative impact of caregiving in comparison to caregivers of patients with depression or schizophrenia[3].

Bodywhys, The Eating Disorder Association of Ireland, was established in 1995 to support people affected by eating disorders. In 2014 they recognised a growing need for informal educational and emotional support for families. The PiLaR programme (Peer-Led-Resilience) was developed to meet this need, in collaboration with the National Clinical Programme for Eating Disorders (NCP-ED).

To date over 613 family members and friends have attended the free, four-week PiLaR programme gaining information, education, and support. The HSE clinical programme strategy identifies value for money as being one of its three core aims. This is embedded in the Eating Disorder Model of Care through its commitment to evaluating service quality. Therefore, in 2018, the NCP-ED detailed Dr Ingrid Holme, a medical sociologist, and Professor Fiona McNicholas, a psychiatrist, based at the UCD Department of Psychiatry to evaluate the PiLaR programme to establish its level of effectiveness and the degree to which it meets the needs of users.

This report provides a short synopsis of the PiLaR programme, the partnership approach and content, along with the formative evaluation findings and recommendations. This study is based on the 1st cycle of an action research process, using a mixed-methods approach. This included informal semi-structured interviews with service users and stakeholders, pre and post feedback questionnaires, and field-note observations (see **Appendix 8.1**). Despite the short duration of the PiLaR programme (8 hours over 4 weeks), this evaluation offers evidence that attendance enhances the knowledge, skills, and to some extent the emotional well-being of participants. This provides grounding for the next stage of development leading to a future summative evaluation.

1. Arcelus J, Mitchell AJ, Wales J (2011). Mortality Rates in Patients with Anorexia Nervosa and Other Eating Disorders. Arch Gen Psychiatry, 68 (7): 724-731.

2. Anastasiadou D, Medina-Pradas C, Sepulveda AR, Treasure T(2014). A systematic review of family caregiving in eating disorders. Eating Behaviors, Volume 15, Issue 3, 2014

3. Martín J, Padierna A, van Wijngaarden B, et al. (2015) Caregivers consequences of care among patients with eating disorders, depression or schizophrenia. BMC Psychiatry. 2015;15:124.

2. PARTNERSHIP BETWEEN BODYWHYS AND THE HSE

Providing support to family and friends has been central to Bodywhys work since its inception in 1995. This was primarily provided through face to face support groups for family and friends and a telephone helpline. To further meet the need for knowledge, understanding, skills and tools, as well as psychological and emotional support, PiLaR was developed in 2014, funded by Genio, an Irish-based non-profit organisation working with government and philanthropy to transform social services. This pilot was delivered in Sligo together with Dr Edmund O'Mahony and Mary Harron from Sligo mental health services and was very well received. The Health Service Executive (HSE) now provides annual funding, and the programme is delivered by two Bodywhys staff.

PiLaR has benefited from the strong partnership between Bodywhys and the NCP-ED, solidified during the development of the HSE Model of Care for Eating Disorders in 2018[4]. The inter-professional and multi-organisational contributors which developed the HSE Model of Care included HSE clinicians, Bodywhys, and the Eating Disorder Clinical Advisory Group from the College of Psychiatrists of Ireland. Bodywhys staff joined the subgroup workstreams and contributed to significant portions of the report including providing artwork. Bodywhys' staff currently sits on the National Oversight Implementation Group, which is the shared forum between both services at national level regarding development and evaluation, around Model of Care and the joint relationship.

(See **Appendix 8.3** for diagrams showing how Bodywhys services support the HSE care pathways for adults and children).

Bodywhys also acts as an education liaison to the NCP-ED by providing service user perspectives and information which in turn enables promotion of PiLaR and its support services. Bodywhys staff also attend and present at NCP-ED training and related training events including participate in site visits to Community Healthcare Organisations (CHOs).

The current PiLaR programme has been formed from both a 'pull' in demand from Bodywhys service users and a 'push' in supply from the NCP-ED. The Model of Care sets out clear goals for this collaboration in 2019 including the continued developing of the national Eating Disorder network of specialist Eating Disorder Teams. The continued activity and cooperation will ensure that Bodywhys programmes such as PiLaR are fully embedded within the Model of Care and the development of the Eating Disorder teams.

4. Report available from https://www.lenus.ie/handle/10147/622758

3. PiLaR

The primary aim of the programme is to address the needs of supporters, parents and family members of people with eating disorder with a specific focus on their need for answers by providing accessible information and facilitating understanding what was going on for their child/loved one (see Box 1).

Box 3.1 - Needs of Supporters

- Information about eating disorders.
- Increased understanding of the associated medical issues in eating disorders and the mind-set of a person with an eating disorder.
- Improved capacity to support in a helpful way.
- Understand what it means that "eating disorders are not just about food".
- How to build resilience.
- A space for themselves to be able to say how hard they find it, how frustrated they are, their lack of understanding and how it frustrates their efforts.

The first PiLaR pilot ran in Sligo 2014 as a 6-week programme and involved three small groups. Refinement of the program was guided by three core questions:

1) what worked?
2) what did not work?
3) what was found by the evaluation?

This enabled the subsequent roll-out of the current model of PiLaR, a 4-week programme to deliver information and support within the areas identified (see Box 3.2, 3.3, and 3.4).

3.1 PiLaR's Aims and Content

The programme aims to increase the understanding and knowledge of eating disorder for all attendees (Aim 1). For those supporters who have some familiarity with eating disorders, the programme also aims to help them recognise their emotions and reflect on their contexts concerning safety and well-being, and give them opportunities to develop their own positive, constructive coping strategies in their lives (Aim 2).

The focus throughout the four weeks of the PiLaR programme is on self-care, which is vital for the people who are supporting a person through recovery from an eating disorder. PiLaR's approach centres on building supporters' resilience by enabling them to understand eating disorders better, including how an eating disorder changes the way their loved one thinks, feels and experiences their world.

As well as the content covered (Box 2, 3 and 4); additional support is offered to PiLaR attendees via Bodywhys support services and a specific PiLaR WhatsApp group.

Box 3.2 – Week 1, 'Understanding Eating Disorders'

- General introduction on how to understand an eating disorder.
- How to understand the dynamics and processes involved in the different eating disorders.
- How to understand the ways in which a person gets caught up in an eating disorder and why it is so difficult for change to happen.
- Kate's story.
- Question and answer session.

Box 3.3 – Week 2 and 3, Core Topics

- Understanding the mind-set of a person with an eating disorder.
- How to help someone to acknowledge they have an eating disorder.
- Distinguishing between the eating disorder and the person being supported.
- Helpful ideas to build support.
- Communication: how to have a conversation.
- Power struggles and how to avoid these.
- Helping a person accept help.
- Dealing with rejection/shutting down/anger.
- Understanding your person's triggers for eating disorder thoughts and behaviours/tackling triggers.
- Managing mealtimes.
- Dealing with getting older.
- Coping with family life/supporting siblings.

Box 3.4 – Week 4, Understanding the Recovery Process

- What does recovery mean?
- What happens in the recovery process?
- What is treatment and recovery like for someone with an eating disorder?
- Moving forward and using support.

3.2 PiLaR Facilitators

PiLaR benefits from having two highly skilled and experienced facilitators. Harriet Parsons (BA (psych), MA, MSc., Reg. Pract. APPI, ICP.) is a fully accredited psychoanalytic psychotherapist and Kathy Downes (BA (psych), P.G. Dip, MSc., Reg. Pract. IFCAPP, ICP) is a fully accredited Child and Adolescent psychotherapist.

Harriet joined Bodywhys in 2005, and is the Training and Development Manager, working to provide the support component to the HSE National Clinical Programme for Eating Disorders. Harriet provides professional training to various professional groups, GPs, psychiatrists, youth workers, foster carers, social care workers and others. She also regularly lectures at 3rd Level on the subject of eating disorders in UCD, TCD School of Nursing and Midwifery. She is a member of the Editorial Board of the APPI Journal Lacunae.

Kathy joined Bodywhys in 2017 and delivered her first PiLaR in the same year. She is the support officer with Bodywhys; her position involves managing all the support services provided by Bodywhys (telephone helpline, face to face support groups, online support groups, email support, SeeMySelf online psycho-education programme), as well as training and supervising the volunteers who work on these services.

Kathy is the Chairperson of the Irish Forum of Child and Adolescent Psychoanalytic Psychotherapy (IFCAPP) and is a registered practitioner with I.C.P. Kathy teaches on the MSc in Psychoanalytic Psychotherapy in Trinity College Dublin and works in private practice in Child and Adolescent psychotherapy.

4. EVALUATING PiLaR

4.1 Current Delivery

613 people in 15 locations around Ireland have attended 23 PiLaR programmes since 2014. PiLaR and group size varies according to location (from 8 to over 40 depending on location).

Year	Location
2014	Cork and Limerick
2015	Cavan and Kilkenny
2016	Cork and Dublin
2017	Dublin x 2, Kerry, Mayo, Cork, Athlone, Waterford, Sligo
2018	Dublin x 3, Limerick, Tipperary, Athlone, Cork, Galway, Cavan/Monaghan, Antrim

The annual programme is organised to ensure geographical spread, and HSE staff are asked to collaborate on dates, to arrange building and refreshments etc. to maintain the partnership approach. Communication between Bodywhys and NCP-ED also occurs on a monthly basis.

PiLaR currently has a monitoring and evaluation process in place. As participants arrived at the venue in week 1 they are asked to sign in, take Bodywhys' booklets etc. and a printout of the slides from the registration desk and fill in a 'pre' programme questionnaire. This gathers information about who the person is supporting, a few details regarding that person's eating disorder and treatment, the participant's expectations of the course, rating of understanding of eating disorder, and space for any specific questions the person would like to be covered in the coming weeks. At the end of the final session (week 4) participants are also asked to complete a second questionnaire. This rates the degree to which their expectations were met, structure of the course, experience of the course, change in understanding of an eating disorder, and confidence about eating disorder and understanding the person they are supporting.

The data gathered from these two questionnaires (week 1 and week 4) was overwhelmingly positive. This included reviews of the content of the programme, the activity of the facilitator, the learning atmosphere etc. Of 10 questions which asked the person to rate statements from strongly disagree to strongly agree, only 4 questions generated any negative ratings and all of these were linked to the participant's competences about eating disorder.

To gain further insight into participant's experiences, the questionnaires were reformatted and modified. 71 participants attending 3 PiLaRs during the autumn and winter of 2018 rated their experience using this newly adapted form. At the start of these two programmes participants were asked to add a code to the top of their week 1 and week 4 questionnaires so they could be linked.

4.2 Who Attends PiLaR?

Attendees have been predominately mothers of young adult daughters who have a diagnosis of anorexia nervosa. Registration data from 2014 to the start of 2018 found that 57% were attending on their own, 39% were attending with one other person from their family, and 4% were attending with 3 family members. The person being supported is also likely to have had a formal diagnosis of an eating disorder, and some experience of CAMHS/AMHS treatment. Since October 2018, parents have made up 87% of attendees, were supporting daughters (78%) or sons (9%) with an eating disorder and the majority were supporting a young person (under the age of 19). Mothers have been the main supporters who attend PiLaR however fathers, grandparents, siblings, extended family and friends also attend and there is a wide range in the supportive relationships who attend PiLaR. The majority of attendees reported that the person has had a formal diagnosis by a health professional of an eating disorder.

4.3 What Are Their Experiences of PiLaR?

PiLaR was very well received by nearly all participants. The programme aims to increase the understanding and knowledge of eating disorders for all attendees (Aim 1) and self-reported measures indicate that this is met (see **Figure 8.1**: 55% strongly agree that their understanding has changed, 32.4% agree). The second aim is to help supporters recognise their emotions and reflect on their contexts concerning safety and well-being, and give them opportunities to develop their own positive, constructive coping strategies in their lives (Aim 2). Again, self-reported measures indicates this occurs; 26.8% strongly agree and 35.2% agree that there has been a change in their own understanding of themselves. 26.8% strongly agree that their behaviour has changed and 39.5% agree (see **Figure 8.1**). The highly positive views of PiLaR were echoed in the qualitative interviews especially of the facilitators which were described as "*very empathetic*" and "*amazing*".

The first time I sat there, she was describing this and that, and this behaviour and that pattern, and I was, like, 'Oh, my God, it's just like living with her. She must know her.' Incredible. She had amazing insight into the illness.

4.4 PiLaR as a Psychoeducational Event

Respondents were very satisfied with the level of knowledge, content and information proved during the 4-week programme (see **Figure 8.2**). They agreed or strongly agreed that it was well structured (95.8%), well presented (98.6%) and understandable (98.57%). Participants felt listened to (90.1%), supported (97.3%), and felt they could ask questions (88.7%). 91.5% felt their expectations were met and 87.3% felt the programme was relevant to their situation and 87.4% felt it was relevant to the specific eating disorder diagnosis of the person they were supporting (See **Figure 8.3**).

While the core content is consistently delivered in all PiLaRs, the material in week 2 and 3 is guided by the questions raised by the audience. 98.6% of attendees felt that the questions that others asked were useful and 87.3% found that it was helpful being with others in similar situations (see **Figure 8.4**). It is important to point out that although 11.3% were unsure about this, no one disagreed with these points.

We also examined the motivations for attending (See Figure 8.5). 60% agreed that they had learnt skills rather than information at PiLaR and coupled with the high scores shown in **Figures 8.1 and 8.2** indicate that there is a good fit with exceptions. 45% would have liked to have heard from experts, however 48% were unsure or disagreed, indicating that this requires further investigation.

Our stakeholder interviews indicated that some clinicians may have some concerns regarding conflicting information being provided regarding specific therapies and clinical advice. However, talk of food and food-related behaviour is discouraged by the PiLaR facilitator. Participants may hear questions from supporters whose situation is clinically critical, i.e. someone in a relapse or a terminal situation. This may shock and upset those who are supporting someone with a different clinical situation. For some parents, this can be the first time they have considered the severity of eating disorders.

I did hear a story which has stuck with me (...) that story stuck with me because I often thought, 'How the hell is she doing now?'

It is also important to note that PiLaR is not a HSE clinical space. Some participants did push for more 'official' clinical information during PiLaR however the questioning was managed by directing the person to consider the underlying emotional need for the information and/or supporting the concern being raised to the clinician.

She [PiLaR facilitator] didn't really say, 'You can do this, and you can do that.' So, that might be one thing that perhaps I might recommend, that there might be a little bit more discussion about what your treatment options are. (...) because I felt that she didn't discuss that at all, really, and because we had already finished family therapy, we had already, kind of, reached that, so in a sense, it wasn't critical for me, but it probably was for other people.

4.4.1 Free, Unrestricted and Open to All

At the heart of PiLaR is a strong commitment to providing a programme which is open to all who are supporting a loved one with an eating disorder. The programme is free, there are no prerequisites (medical referral or a diagnosis) or restriction (type of eating disorder or age of person), and while it might be held in an HSE location (hospital etc.) and promoted within local HSE mental health services Bodywhys is clearly marked as the provider.

Supporters can attend multiple PiLaRs, and the facilitators will also allow other

family members and/or friends to join the programme after it has started. Indeed, in some cases, one parent has registered in week 1, and in week 2 their partner has attended instead etc. Informal conversations with those who have attended PiLaR and professionals has identified that the provision of PiLaR as an open programme connects to both positive factors and challenges.

These factors produce a highly fluid and dynamic attendee cohort. The open-ended questions from week 4 and the informal conversations reveal some positive aspects and challenges.

> *(...) some people are thinking, 'Oh, God, I think my daughter, or my sister, or whatever, might have an eating disorder,' and the other person is saying, 'I've been dealing with this for 15 years, and I can't get her to go for help,' and whatever, and that makes it very hard, I'd say, to try and tailor something in the middle.*

This fluidity leads to flexibility about who can attend and when, and it can also result in duplication of previously covered material. However, the open-ended questions on the week 4 feedback sheets show that many participants actively intend to participate in future PiLaRs indicating that duplication was a minimum concern.

4.4.2 Promoting Lay Expertise

A key message of PiLaR is that for people to effectively support their loved ones with eating disorder, they do not need to become 'academic' experts in eating disorders (see **Figure 8.6**). With better communication skills and basic knowledge of eating disorder, they can become experts in the eating disorder as experienced by their loved one. PiLaR facilitators emphasises that each person experiences eating disorders in their own particular way and they will have (somewhat) unique habits and thoughts. Supporters can benefit from understanding their loved one's lived experience of the condition, and they can become experts in this lived form of the eating disorder. This lay expert-hood is recognised by only a small number of the participants (see **Figure 8.6**: 62% disagreed that they were experts in the eating disorder of the person, 28.2% were unsure, and 7% agreed). However, PiLaR may be the first time that supporters have considered that they could gain this type of expertise. Indeed, the qualitative interviews indicated that participants can feel that attending PiLaR is only the start a longer process of gaining understanding of the experiences of their loved one and that some were secure in this type of claim to expertise.

> *I always say to people, I said, 'I'm an expert on my daughter's anorexia alone,' but everyone's is different, unfortunately.*

4.4.3 Advocating "Recovery is Possible"

A core take-home message is that 'recovery is possible' (See **Figure 8.7**). While the majority of participants internalise the PiLaR's message of 'recovery is possible' (29.6% strongly agreed, 54.9% agreed), 14.1% remained unsure if recovery was possible. This indicates that there remain some attendees who have concerns about where to access care and the degree to which recovery is possible for everyone.

54.9% were confident in supporting their loved one with 32.4% being unsure and 9.8% disagreeing. However considering their own personal capacity (as a parent/carer) to support their loved one, 83.1% agreed they had capacity while 11.3% were unsure.

64.8% felt they knew where to turn for support, with 32.4% disagreed or were unsure of where to turn to for support. This could indicate that they were unsure of Bodywhys role, or support within clinical structures, however, this requires further investigation.

The interviews suggesting this is due to a belief that an eating disorder is a lifelong diagnosis. We feel that responses to this question reflected the stage of the patient journey and connects to the response given concerning supporting the person.

For some, as over, the message was not strong enough.

It's a bit like, 'Recovery is possible, you know, it really can happen.' It's almost a bit like it's not positive enough. It's, like, in those vague, random cases and those really lucky people, recovery is possible, whereas I think it could be more positive than that.

For others, supporting someone with greater clinical need, recovery was unattainable. Providing online examples of what recovery means for different people with eating disorders may help.

4.5 PiLaR as Mental Health Support for Supporters

75% of participants felt that supporting someone with eating disorder was impacting on their own mental health while 14% were unsure (See **Figure 8.8**). Participants can be supporting someone who is in the in the middle of a complex clinical situation, someone who is relapsing or someone who is waiting for treatment.

This is a highly uncertain time for both the person being supported and the supporter. Our interviews indicate that in some cases the mental health needs of close family members may exceed that which can be provided for within a group psychoeducational programme.

For some participants, PiLaR enabled them to draw boundaries and start to manage their own wellbeing as separate from eating disorder.

I feel that I can support my daughter without letting her illness demand everything from me.

I feel a lot calmer and a lot more confident to support my sister in what she's going through. Initially, I felt very emotionally raw, but now I feel I have a better understanding of eating disorders and how to cope with my sister's behaviour.

I feel I have got a better understanding of what my daughter is going through. I'm not lying awake each night anymore.

So, it's everything you have to go through, it's definitely adding stress, and your mood goes down. [You are] worried that they are going to die.

The accompanying role undertaken by the supporter on the patient journey can be decades long and repetitive.

She has again been admitted (sectioned) and the tube feeding has begun. This happens at the same time more or less every year

Intervening with mental health psychoeducation at an early stage builds resilience and positive coping strategies for those caring for a loved one with an eating disorder as a chronic condition.

The level of mental health distress as a result from caring for a loved one may reach clinical levels of pathology and meeting these needs will remain beyond the scope of the PiLaR program. However, it can play a role in identification of these needs and signposting to appropriate services. Furthermore, PiLaR may be able to provide some interim support while the carer is awaiting their own services, and Bodywhys has a critical role to play in advocating for these services.

5. LIMITATIONS AND STRENGTHS OF FORMATIVE EVALUATION PROCESS

Evaluating a bottom-up dynamic programme presents some challenges. This report will help direct the development of the PiLaR programme and as such the report presents only the relevant sample of the data related to the experiences of attending the programme. Three points should be noted.

1) The quantitative data was gathered using un-validated subjective self-report questionnaires which were completed at the venue directly before and after the programme. Future evaluation might include assessments of factual knowledge gained for the person attending PiLaR. (See **Appendix 8.1** for additional comments regarding the limitations of specific questions).

2) Participants perceived that PiLaR impacted positively on the lives and wellbeing of those with eating disorder, for example:

> *She has become a lot more willing to talk and give an insight into her eating disorder thoughts, her motives behind her actions and what she is struggling with.*

However, no objective data was collected that allowed an evaluation of the impact of the PiLaR on the individual with an eating disorder. Future evaluation may seek to address this by including objective measures (such as person's BMI, quality of life or engagement in treatment as an outcome of psychoeducation (attitudinal change).

3) Current PiLaR monitoring data is limited to the end of program, collected at week 4 and therefore does not allow for an assessment of duration of effect. Evaluation should be collected again at various time frames (e.g. 3-6 month follow-up). Supports need to be followed up 3 months after to assess the longevity of PiLaR's impact.

6. RECOMMENDATIONS

Based on this 1st action research cycle we make the following recommendations;

Marketing and Advertising

- PiLaR remains 'open to all' and free for attendees. Building solidarity and a sense of community are a core values, and we feel these should be maintained.

- Segmentation of participants should be considered to manage expectations. This could be achieved by running biannual age-specific PiLaRs in each location. For example, a Spring PiLaR focusing on those supporting younger persons and an Autumn PiLaR focusing on those supporting 18+. Supporters would be able to attend as they wish, but that they are made aware that the focus in this particular programme is on younger or older individuals. This could be achieved by running a pre-session for supporters of newly diagnosed loved one. This group may require introduction into the HSE clinical services etc.

- Staff within CAMHS and AMHS should become active advocates for PiLaR This may include sharing the findings of this evaluation widely within Mental Health Services to enable increased awareness within the new Model of Care regarding PiLaR. The Model of Care recommends a Bodywhys link with each Eating Disorder team nationally, and we suggest that an individual is identified on each team to undertake promotion and raising awareness of the programme.

- Bodywhys staff should be supported to promote PiLaR within clinical and academic spaces. This also requires that Bodywhys are able to access funding for training and conferences attendance to promote the PiLaR programme.

Content Development

- PiLaR facilitators are objective and must remain that way for PiLaR to be a helpful space. This includes keeping week 2, 3 and 4 as a space only open to supporters.

- Online tools and media should be developed. This may include adapting existing material and also developing new material such as podcasts from clinicians. There is also the possibility to provide a 'book' of letters from using material sent to Bodywhys.

- Skills-based work is incorporated. This may require an additional week or follow up session.

Partnerships

- PiLaR is a powerful way of obtaining very real feedback to enhance services and address concerns. Thought should be given to the possibility of developing a way in which Bodywhys can feedback issues / concerns to clinicians in the areas, and they can get feedback.

- Further Patient and Public involvement is developed. This may occur by forming an advisory group of supporters, and Bodywhys members feed into development and evaluation.

- A formal evaluation is undertaken during the next cycle. The methodology should be developed in discussion with the partners, but a formal pre and post-assessment should be considered. One approach which may be considered is that of cohort association with records being kept by the clinical teams of attendances and clinical change. This would enable an assessment of the difference between the cohort who did and didn't attend from a clinical outcome / engagement perspective. However this methodology is likely to change the underlying values of PiLaR as a programme which is open, supportive and external to the NCP-ED.

Development of Outcomes and Indicators

- PiLaR has developed in response to the needs of supporters and has proved very effective in responding to these demands. Analysis of the feedback sheets and the qualitative interviews indicates four core areas where supporters have unmet needs. We recommend that these needs are mapped to outputs and outcomes as the programme moves into the next cycle. This will create a set of formal outputs and outcomes. We suggest a set of four (see **Figure 6.1** below), however further work in the second cycle should develop these further (see **Appendix 8.4**).

Figure 6.1: Mapping PiLaR outputs and outcomes

7. CONCLUSION

PiLaR and Bodywhys has been very successful in setting up a psychoeducational programme which introduces the topic eating disorders to those supporting, or wishing to support, a friend or family member. The programme also succeeds in creating an open and supportive environment for people to ask questions and deepen their understanding. At the moment it does not seek to provide group work or (hands-on) skills-based training. As the National Clinical Programme for Eating Disorders builds a robust model of National Eating Disorder service and network of teams, PiLaR will develop, both regarding scale and content and, we suggest, by developing online material.

We recommend that a further action research cycles take place leading to a robust evaluation. Bodywhys should continue to ensure that a wide range of stakeholders remain actively involved in agreeing the programme structure, its management and implementation. Since 2014 the PiLaR Programme has provided a unique insight into the multitude of challenges that Irish families and friends face when caring for a loved one with an eating disorder. If supported by appropriate funding and resources, we feel PiLaR will continue to play a strong role in building resilience in carers as they support their loved one in engaging in treatment services and towards recovery from an eating disorder.

8. APPENDICES

8.1 Methodology

An evaluation having been commissioned by the NCP-ED, in August 2018 a collaboration with Child and Adolescent Psychiatry at UCD was established to produce a scoping exercise to feed into monitoring and evaluation of PiLaR for the next five years. Terms of reference were agreed with regard to analysis of existing feedback data, develop further feedback tools and carry out limited qualitative interviews. Dr Ingrid Holme, a medical sociologist, and Professor Fiona McNicholas, a psychiatrist based at the UCD Department of Psychiatry carried out the analysis and participated in monthly review meetings with Harriet Parsons, psychotherapist and Training and Development Manager at Bodywhys and Ms Rhona Jennings Programme Manager to review objectives and the work plan.

An Action Research Methodology[5] was used, with this work relating to one cycle of the process. Quantitative analysis of existing material was carried out using Excel, producing descriptive statistics. It should be noted that while the majority of questions were answered, in some cases these were left blank (2.2% overall missing data for the questions reported in this report). Five questions which required rating statements had 3 or more non-respondents, potentially signalling that these require adapting in future action research cycles.

- I felt I could ask question
- My understanding of eating disorders has changed in the past four weeks
- I am confident in supporting my loved one through this
- I learnt skills rather than information at PiLaR
- I would have liked to hear from experts during PiLaR

Modelling was not attempted as the focus for this cycle was to develop revised pre and post feedback sheets to gather robust quantitative data in future cycles. Qualitative interviews were carried out as informal conversations with key staff and a small selection of attendees.

An ethics exemption was granted by UCD to gather and process this data as it related to professional views and/or attending the psychoeducational training. Qualitative data was analysed pragmatically, and quotes are shown in this report to highlight illustrative points. In addition, Dr Holme attended a number of PiLaR sessions as observer (week 1, 2 and 3 of Dublin 2018 October) to gain first-hand experience of the programme.

5. MacDonald, Cathy. "Understanding participatory action research: A qualitative research methodology option. " The Canadian Journal of Action Research 13, no. 2 (2012): 34-50.

8.2 Output of Quantitative Analysis

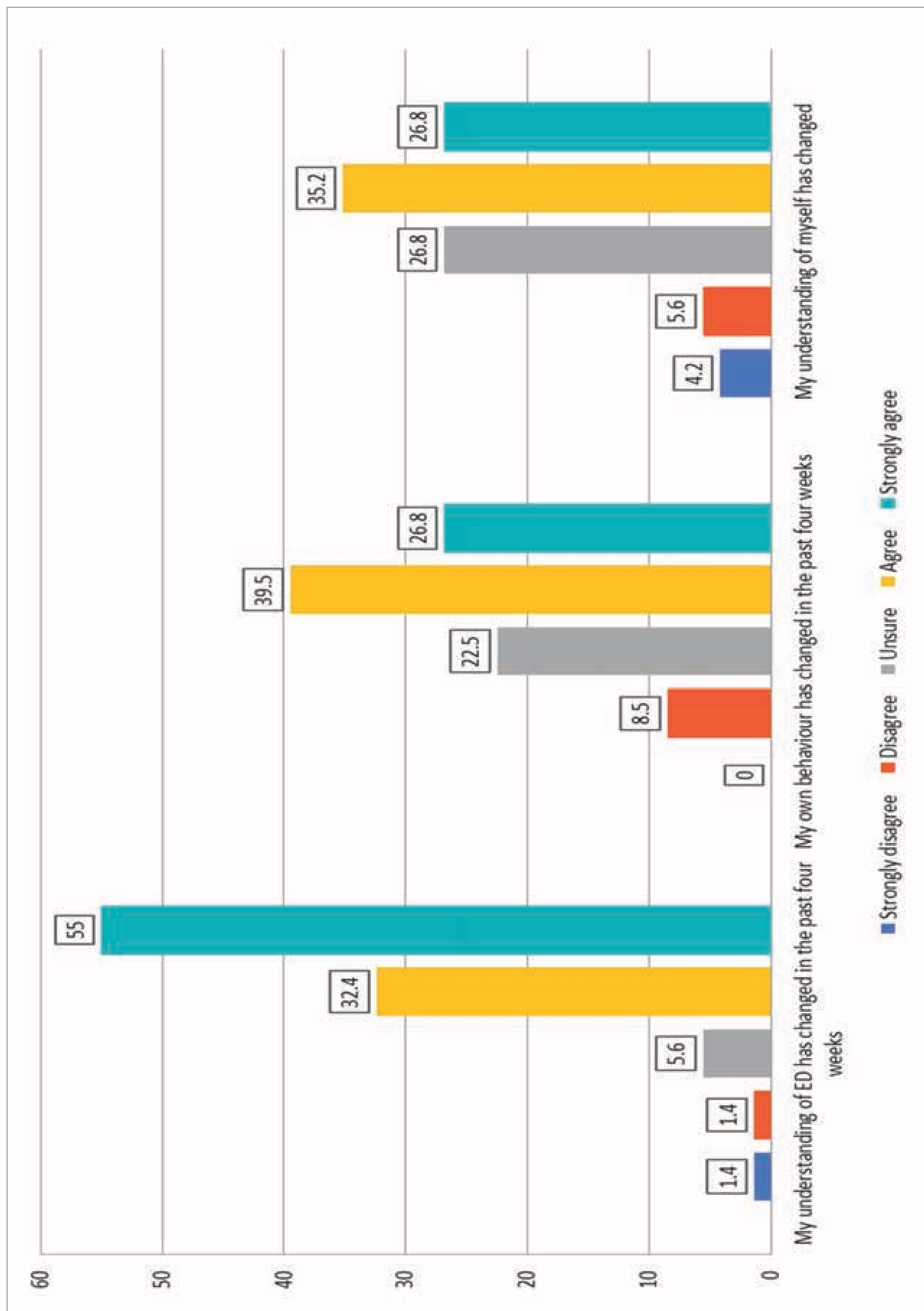

Figure 8.1: Self-reported changes

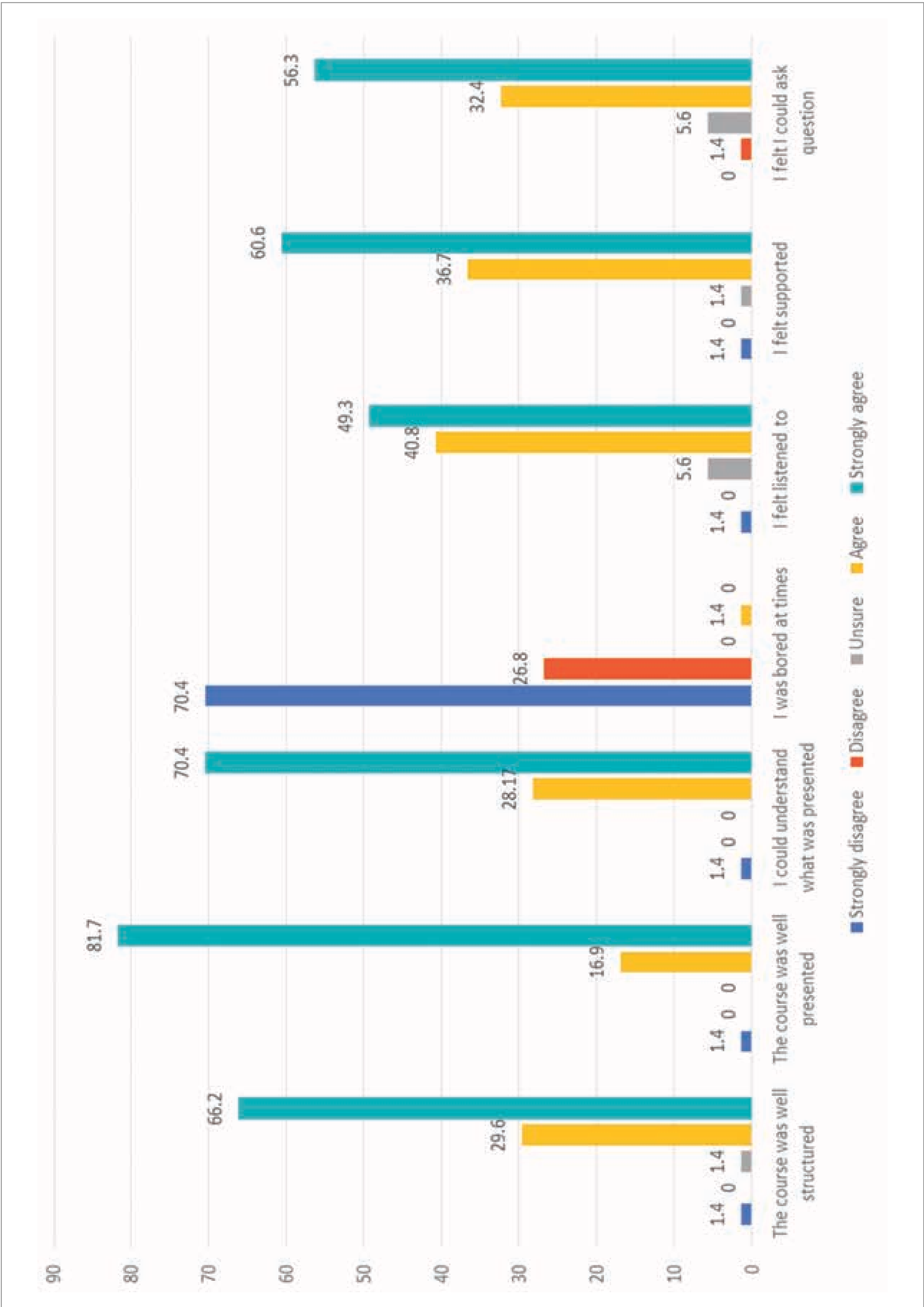

Figure 8.2: The look and feel of the course

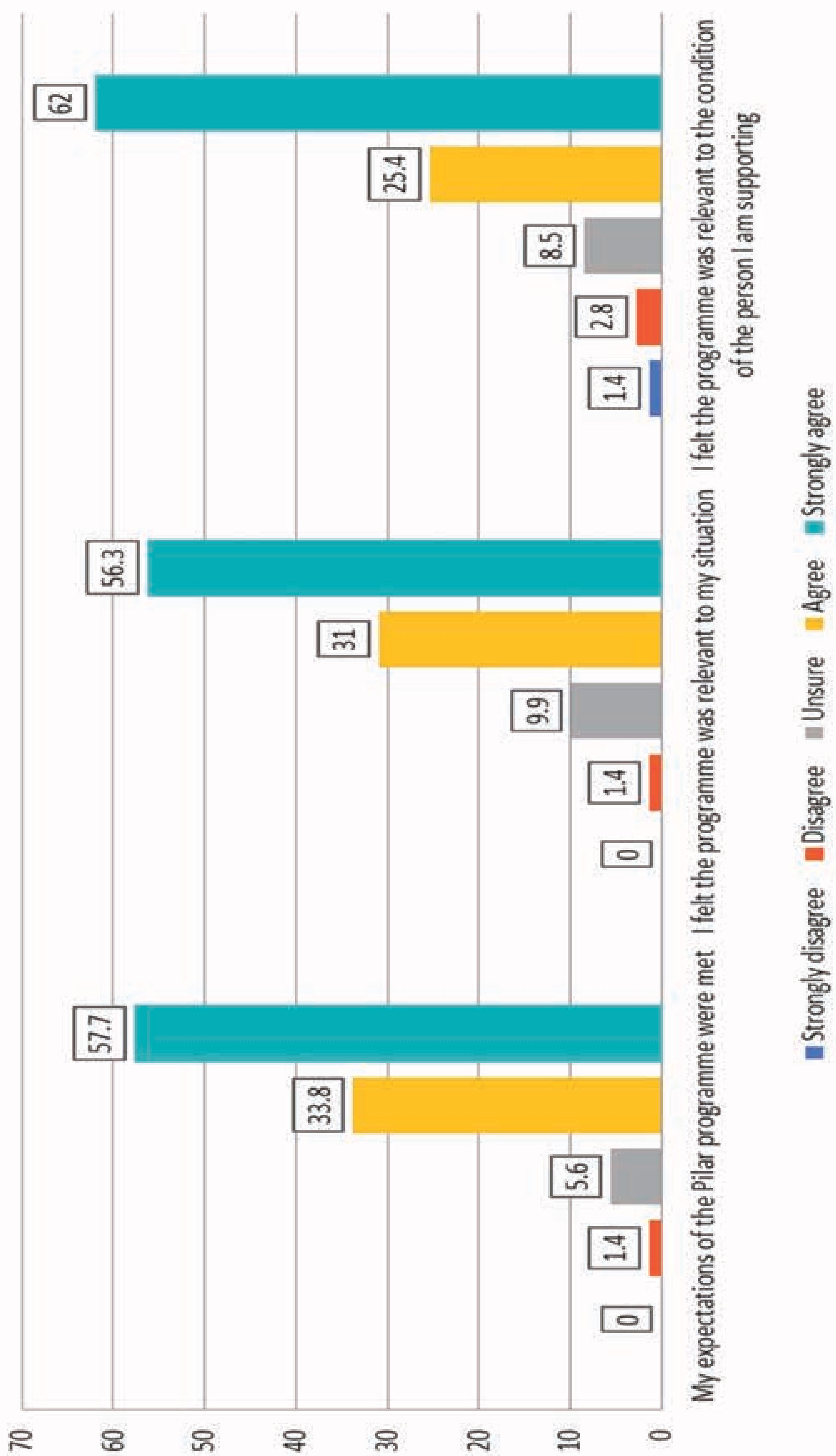

Figure 8.3: The fit between the course and participants' need

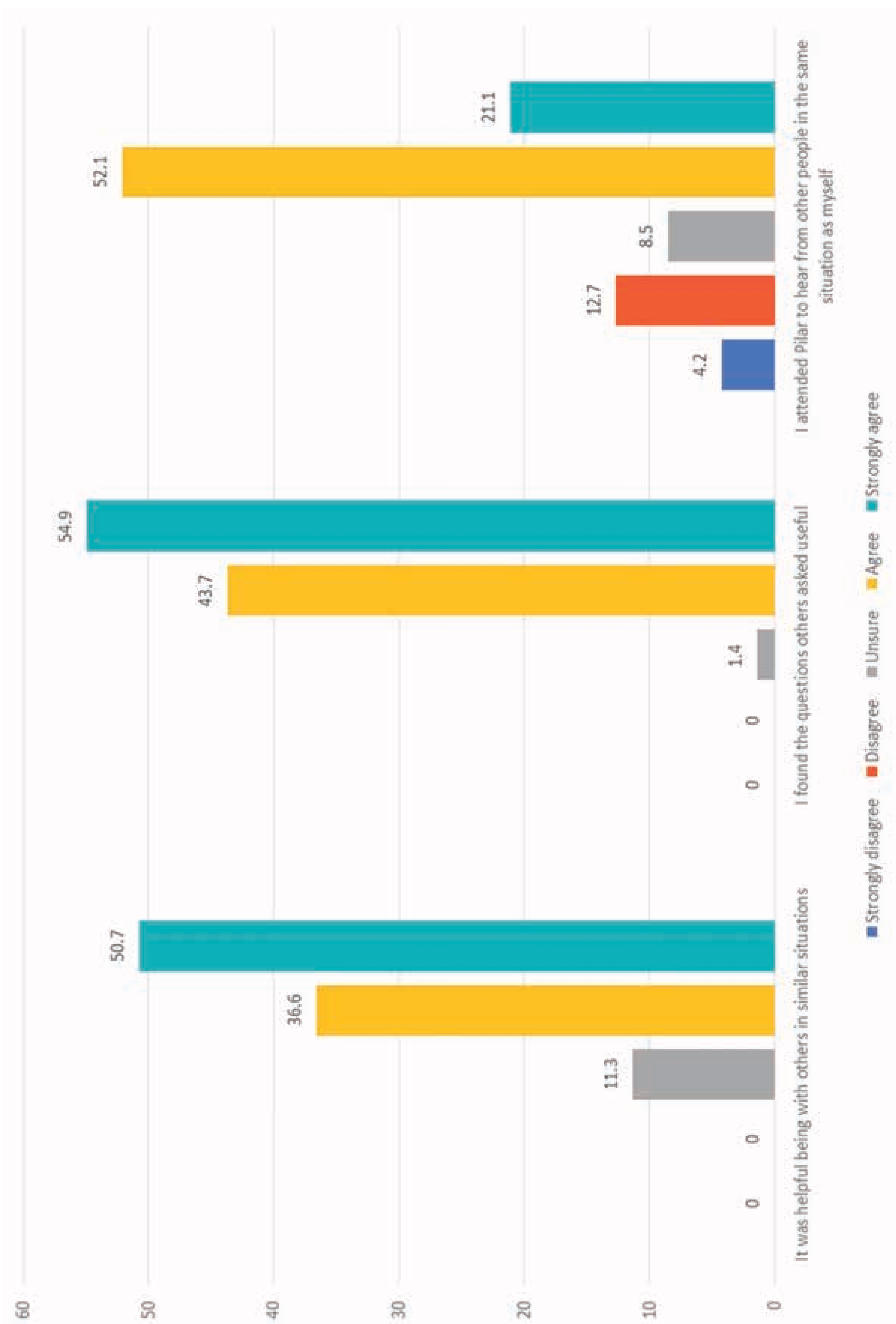

Figure 8.4: The fit between motivation to attend, peer group and the value of peer support

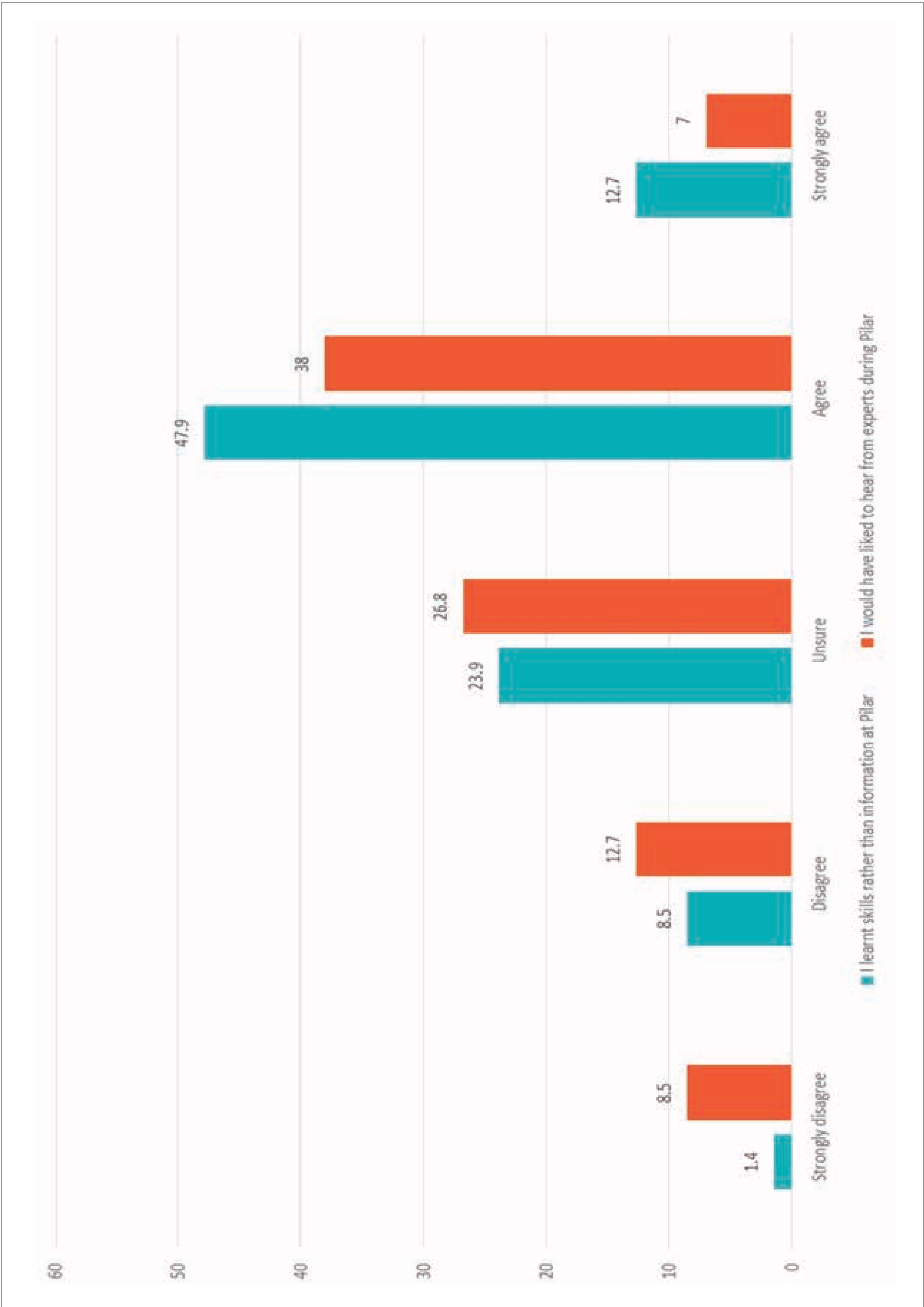

Figure 8.5: Motivation for attending; skills, information or experts?

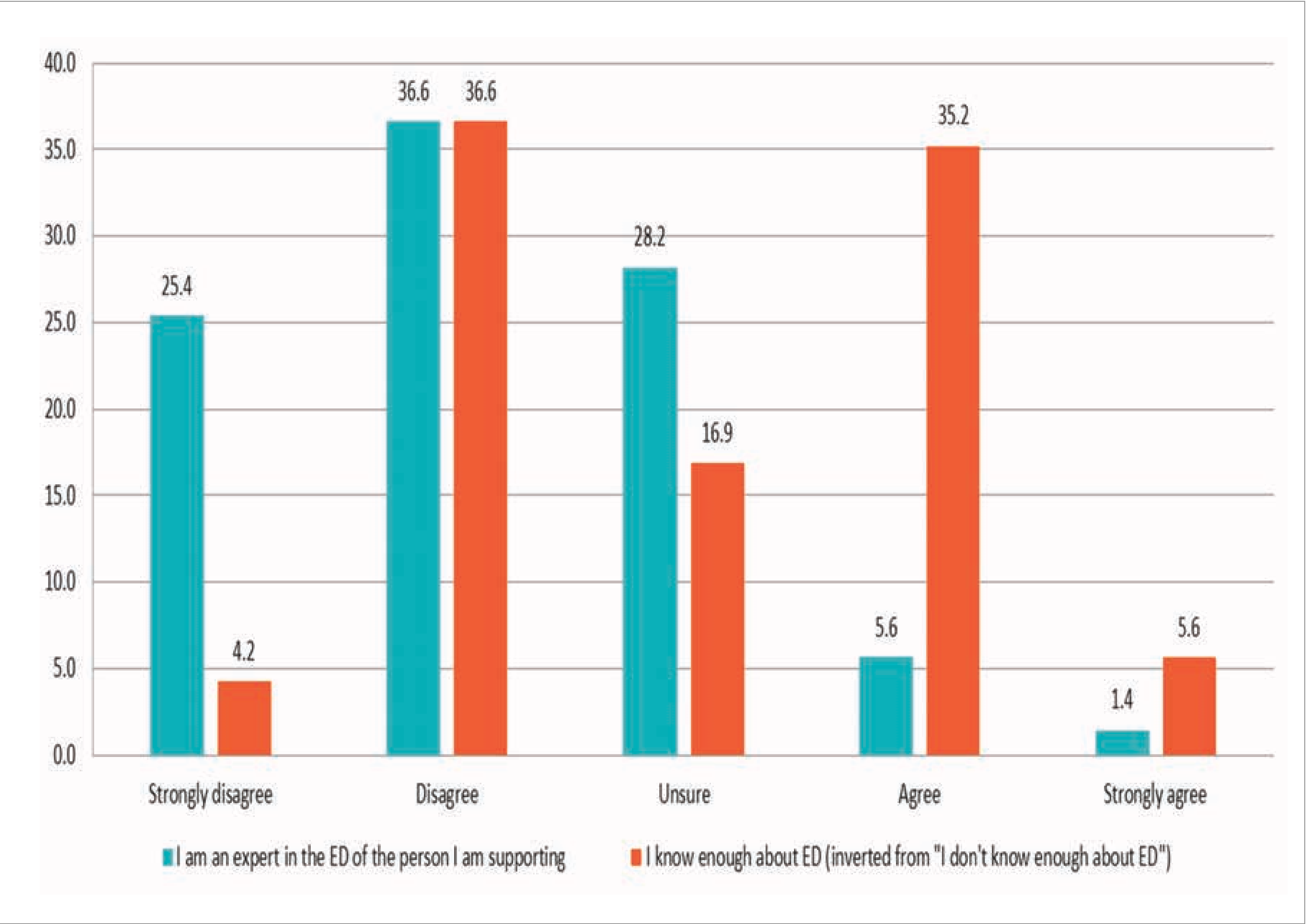

Figure 8.6: Being an expert

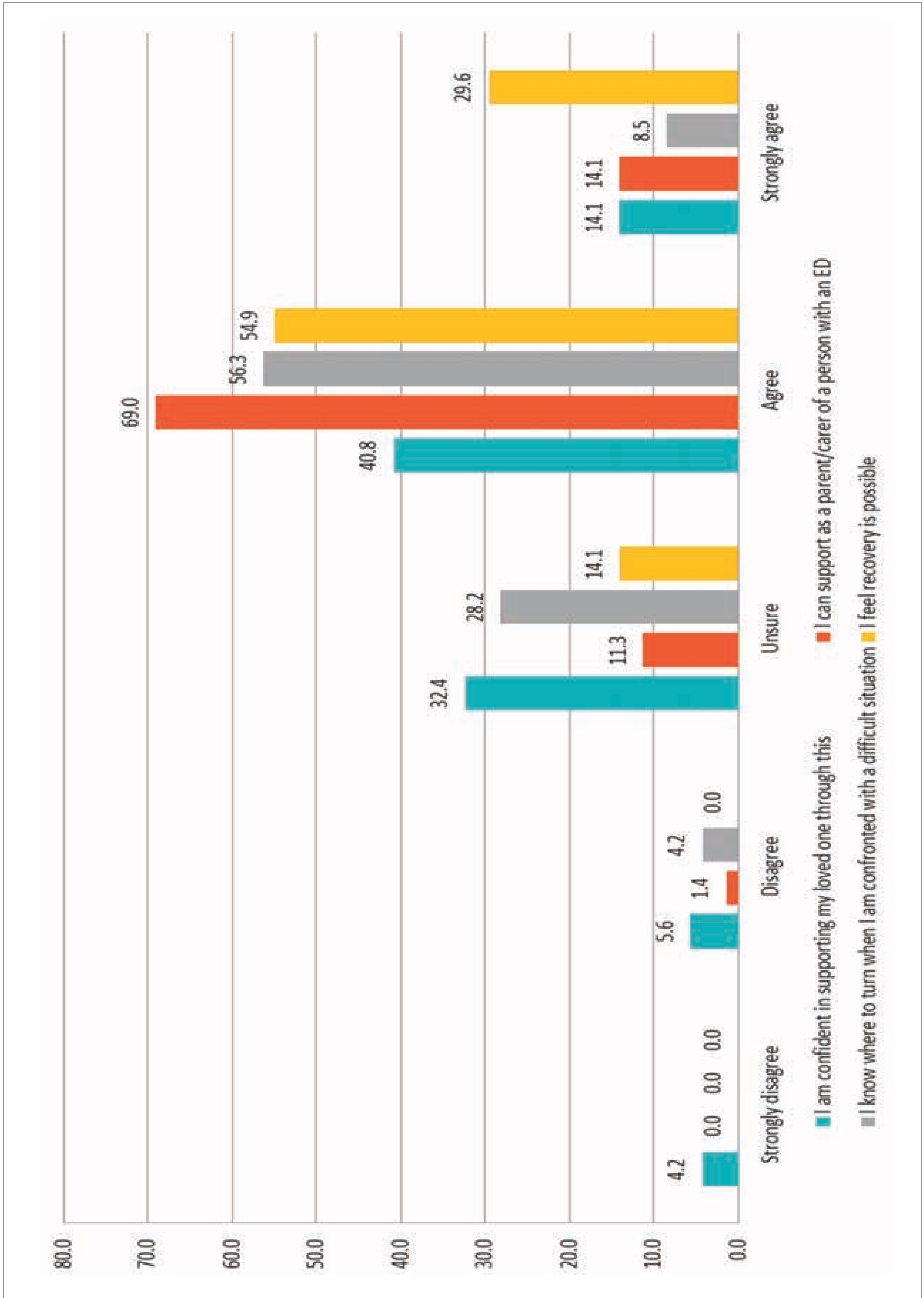

Figure 8.7: Supporting and recovery

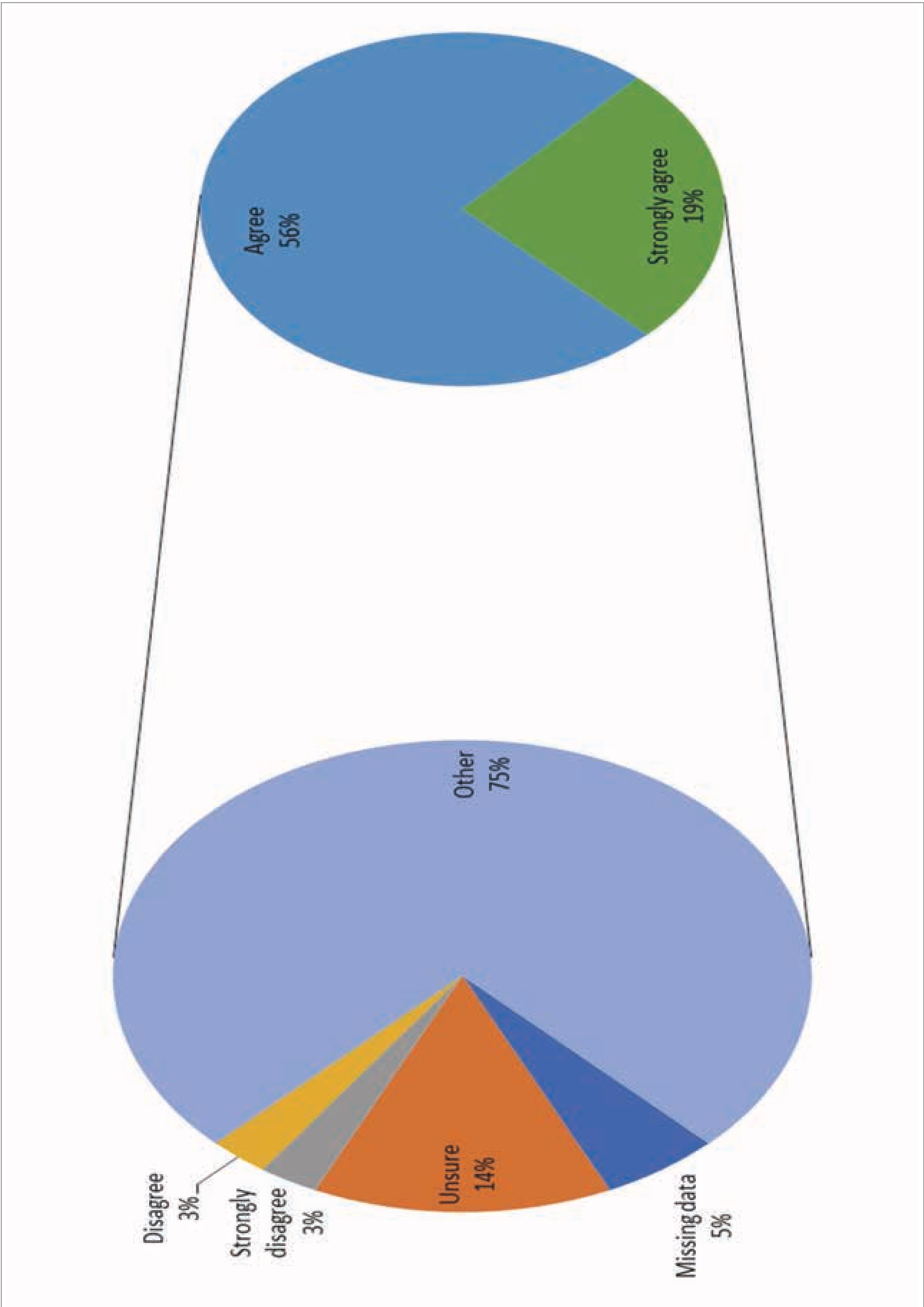

Figure 8.8: Mental Health Needs of Supporters

8.3 Proposed Care Pathways within the Model of Care

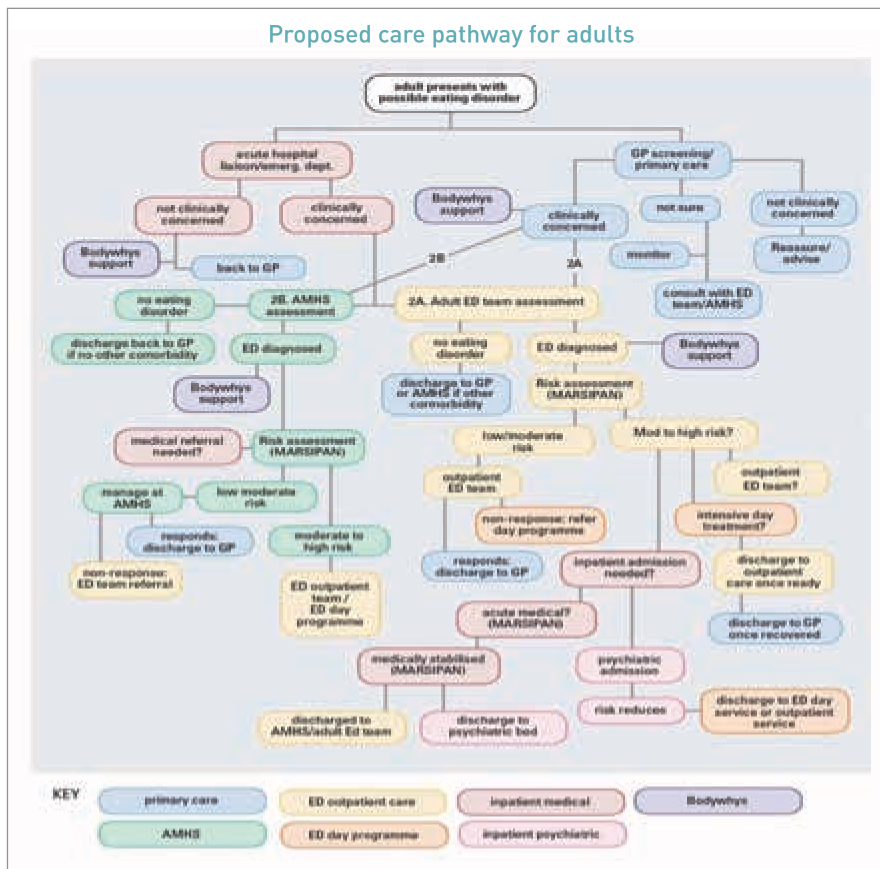

Figure 8.9: Proposed care pathway for adults indicating the relationship with Bodywhys services

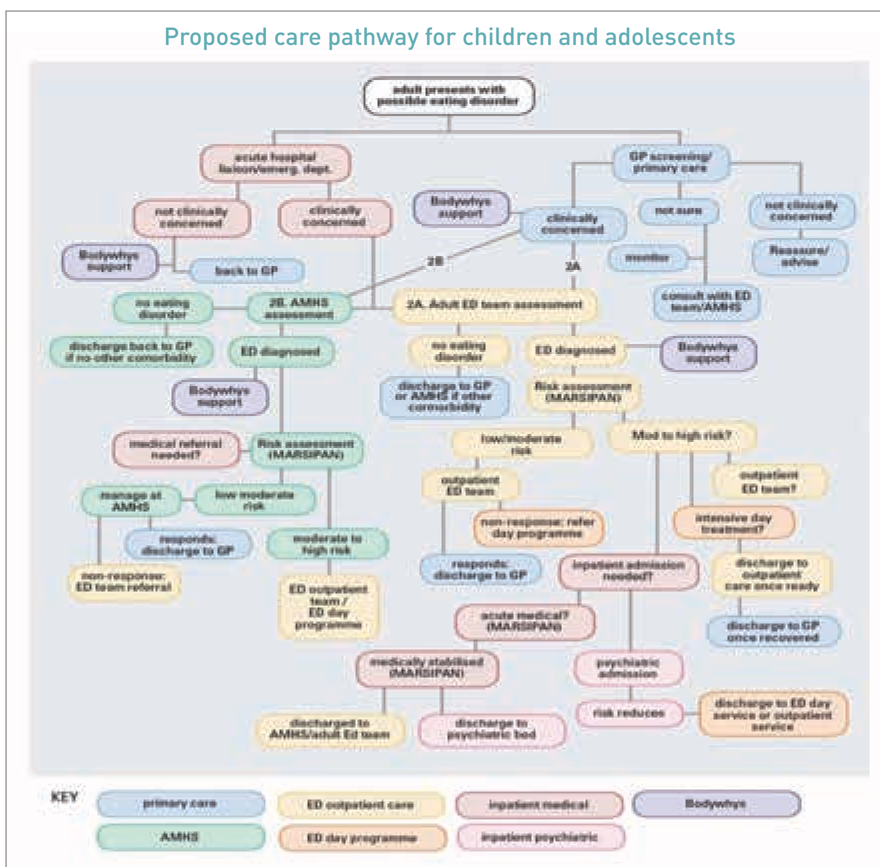

Figure 8.10: Proposed care pathway for children indicating the relationship with Bodywhys services

8.4 Suggested Future Action Research Cycles

Cycle 1:

Formative evaluation to

a) assess current activity,

b) formulate recommendations regarding any changes to programme (suggested action: adding week 5 and online material) **[Complete]**

Cycle 2:

Development of material identified in cycle 1 (tested and refined over 2-3 PiLaRs) and agreement regarding the level of output expected from PiLaR in consideration of the funding and staffing for the programme.

Cycle 3:

Development of robust tools which meet the needs of all relevant stakeholders (tested over 2 PiLaRs) for use in a stepped-wedge trial.

Cycle 4:

Evaluation of

a) outputs of PiLaR,

b) outcomes for participants and others in their wider context (clinical staff and the person they are supporting).

NOTES

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Health Service Executive (HSE)
Dr. Steevens' Hospital, Steevens Lane,
D08 W2A8, Dublin 8, Ireland

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