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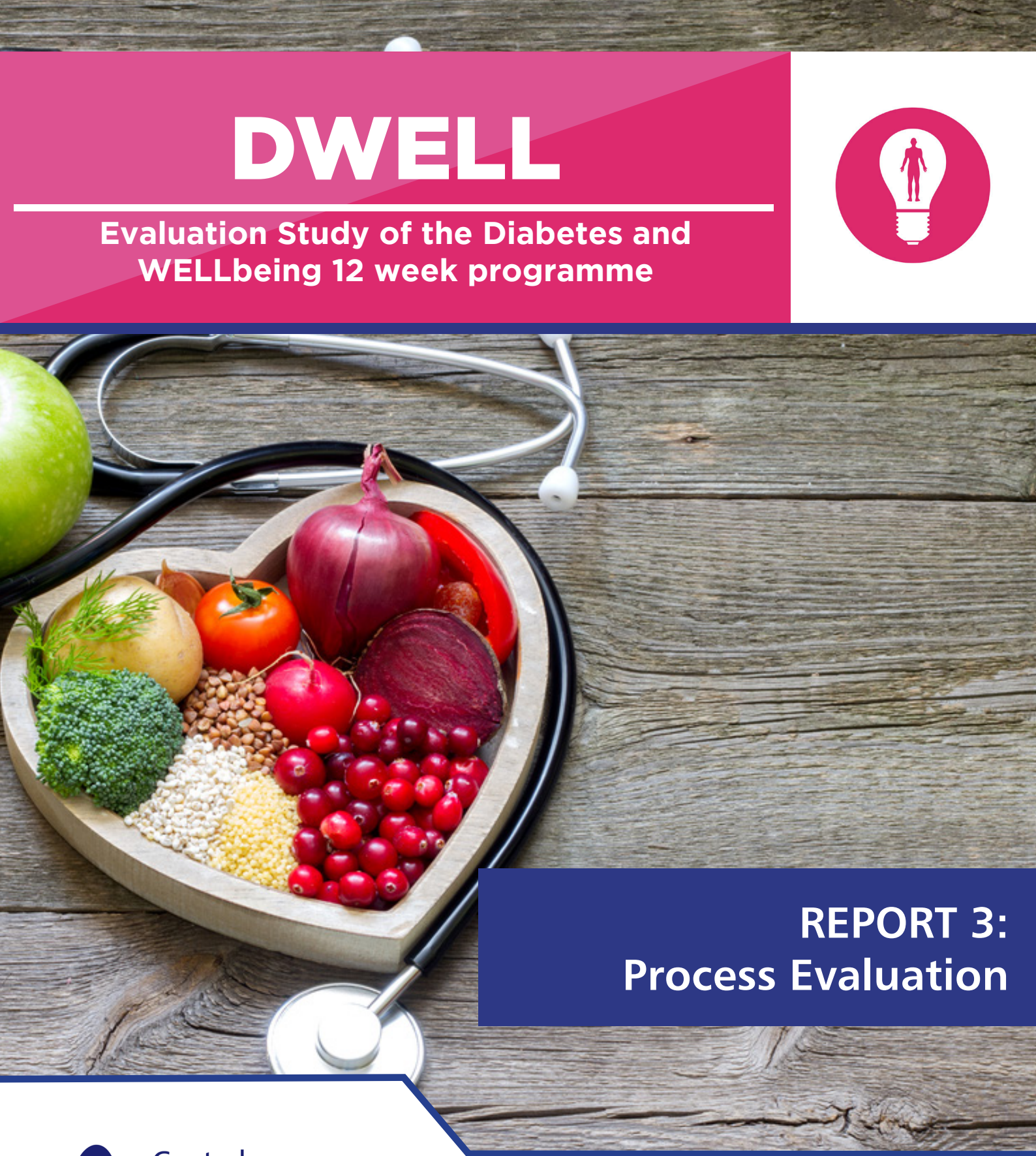
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DWELL

Evaluation Study of the Diabetes and WELLbeing 12 week programme



REPORT 3: Process Evaluation

Canterbury Christ Church University

Interreg 2 Seas Mers Zeeën
DWELL
European Regional Development Fund

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FOREWARD

The Diabetes and Well Being in Europe (DWELL) project was funded by the INTERREG 2 Seas Mers Zeeën Programme and ran between 2016 and March 2023. The overall aim of the project was to empower people living with Type 2 Diabetes Mellitus (T2DM) to enhance self-management of illness through a co-produced 12-week educational programme, and to improve targeted aspects of individual health and wellbeing. The project involved partners in the UK, France, Netherlands and Belgium.
Canterbury Christ Church University ('CCCU') led Work Package 4: Evaluation of the DWELL programme, which commenced delivery in 2018. The evaluation comprised four key areas: patient outcomes; system/process benefits of the programme; staff training; cost benefits of the programme.

For Output 4.1 of this Work Package, we present a set of four final project reports which relate to DWELL programme evaluation. These are as follows:

- **REPORT 1:** Evaluation Methodology
- **REPORT 2:** Participant Outcomes
- **REPORT 3:** Process Evaluation
- **REPORT 4:** Workforce training and Cost Effectiveness

Report 3 presents the Process Evaluation of the DWELL programme, focussing on implementation, mechanisms and outcomes o the programme delivery, captured by qualitative data collected throughout the project.

We would like to acknowledge colleagues for their valuable contribution as researchers and advisors at earlier stages of the evaluation study: Dr Marlize De Vivo and Prof Kate Springett, Canterbury Christ Church University; and, Dr Katrina Taylor, University of Kent.

We are grateful to all DWELL programme participants in the four project countries for their significant contributions and support in evaluating the DWELL programme at all its stages.

We would like to thank all our project partners for their invaluable help in data collection and in particular:

UK - Julie Webster, Anne Eltringham-Cox and Jane Redding, Medway Community Healthcare; Nathalie Belmas and Sue Shaw, Blackthorn Trust; Stephen Cochrane, Kent County Council
Belgium - Ruben Vanbosseghem, Anelien Callens and Veerle Luyens, Arteveldehogeschool
France - Marie Duezcalzada, Jerome Cazier and Dr Véronique Averous, Centre Hospitalier de Douai
The Netherlands - Maarten Gijssel, Linda van Wijk, and Melvin Franken, Kinetic Analysis

This work was funded by the European Regional Development Fund under the Interreg 2 Seas Mers Zeeën Programme [2S01-058].

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Executive Summary

Process evaluation of the DWELL programme allowed an in-depth understanding of the key mechanisms of implementation, mechanisms and outcomes.

DWELL Implementation

- Motivating factors for participants to engage with the programme were: better management of their diabetes; experiencing negativity such as stigma and feeling dismissed by healthcare providers; being referred to the programme by a healthcare professional; and wanting to meet others with the condition.
- The DWELL programme enhanced health literacy and self-efficacy of participants.
- Programme set up was effective and flexible. Reported issues regarding content in relation to the wellbeing and physical elements were addressed by the teams. There were also some operational and logistical barriers such as lack of follow-up (for participants) and resources and recruitment (for staff). Adjustments by sites during the project included: facilitation; content; session timings; recruitment strategies; resources; and allowing partners of participants to attend sessions.
- The DWELL programme compared favourably to other educational programmes for type 2 diabetes that participants had previously attended.
- Differing contexts across countries and sites impacted on how the DWELL programme was implemented. The COVID-19 pandemic created challenges in implementation during that period, namely, substantial difficulty in recruiting participants to the programme and making changes to the set up and mode of delivery. However, for many participants, the DWELL programme provided the opportunity to maintain a sense of normality and interact with other participants in person after lockdown restrictions were lifted.

DWELL Mechanisms

- DWELL incorporated key mechanisms to facilitate empowerment and better self-management of participants: peer support, motivational interviewing (MI) and goal setting
- The effectiveness of peer support came out very strongly in both the focus group and interview data across all delivery sites. A sense of community was established through facilitators ambassadors and participants sharing problems and solutions, working together and motivating each other
- The most applied MI principle was establishing willingness to engage in the programme
- DWELL Participant Goals had four overarching themes: Management of Illness, Management of Nutrition, Management of Physical Activity and Management of Wellbeing
- Goals set by majority of participants across all sites at the start of the 12-week programme were in relation to Management of Illness
- Five particular goals participants identified were: Metabolic Health, Diabetes Education, Physical Activity and Mobility, Nutrition Education and Empowerment and Mental Wellbeing

DWELL Outcomes

- Qualitative feedback illustrated significant positive outcomes of the DWELL programme:
  - Enhanced self-management of diabetes
  - Making important lifestyle changes
  - Enhanced wellbeing (for programme participants and DWELL ambassadors)
- Sustainable outcomes were elicited from 'legacy' participants:
  - Recognition that progress is not a linear journey
  - Sustained empowerment and autonomy
  - Navigating challenges during the COVID-19 pandemic
- Participant recommendations for programme delivery in the future include:
  - Provision of follow-up support
  - Considering online or blended delivery of the programme

1. Introduction

Good practice in public health research is synonymous with the inclusion of a process evaluation alongside an outcome evaluation. Data collected as part of the process evaluation explain the outcome evaluation results (Munro and Bloor, 2010). Process evaluations aid our understanding of how and why public health interventions work (or do not work), which in turn has implications for both research and practice (Linnan and Steckler, 2002).
Moore and colleagues' (2015) guidance was adopted to develop process evaluation of the DWELL 12-week programme. This framework builds on earlier United Kingdom Medical Research Council (MRC et al., 2014) guidance for developing and evaluating complex health interventions. Three key components and the relations between them define the framework - context, implementation, and mechanisms.

This report is structured in alignment with the DWELL Logic Model (see Report 1: Methodology) which informs the intervention and process evaluation. Therefore, the results are divided four sections: context, implementation, mechanisms and outcomes.

Figure 1 below shows how the Process Evaluation Framework was applied to the evaluation of the DWELL programme. The first component of the framework describes the intervention and the factors which may facilitate or hinder its implementation (the context). These factors are external, such as the DWELL site settings and wider healthcare practices and regulations. The second component refers to how the programme was implemented and adapted. In the case of DWELL, this includes the delivery teams, venues and resources. The third component of the framework explores the mechanisms through which interventions bring about change. For DWELL, this includes motivational interviewing and peer support. The final component is the outcomes, i.e. the impact that DWELL had on participants, including those completing the programme, DWELL ambassadors, site leads and facilitators.

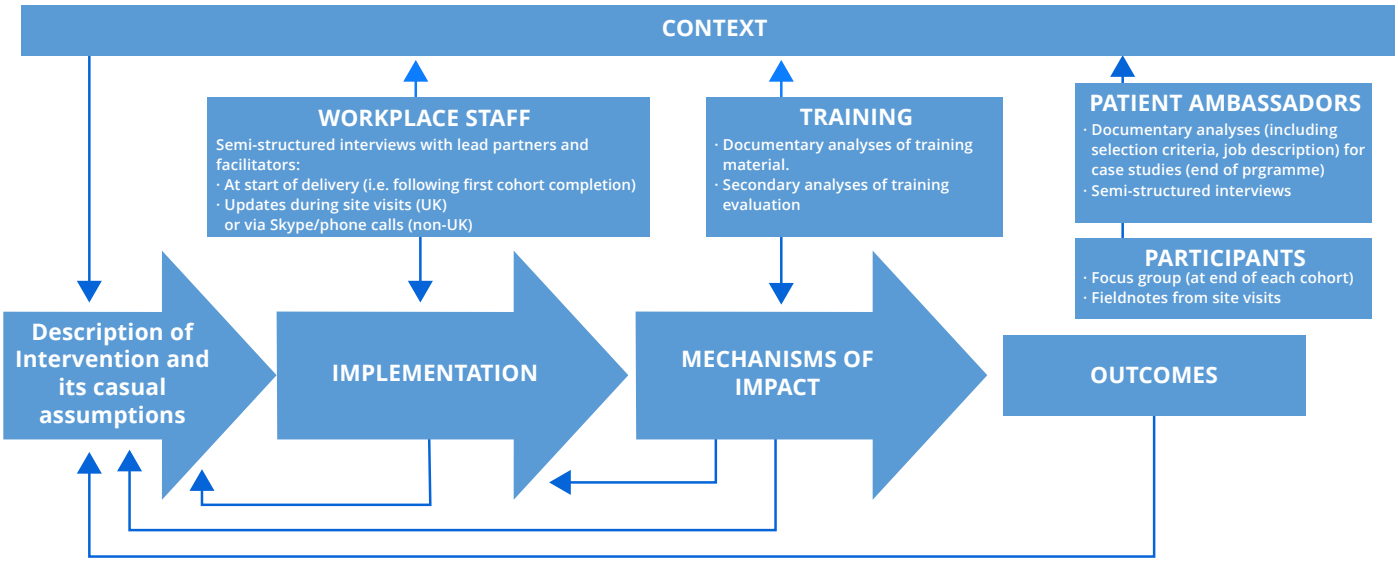


Figure 1 Application of process evaluation framework to DWELL evaluation

2. Methodology

The process evaluation components were assessed by gathering information from key groups and sources involved in the intervention:

1. Participants attending the 12-week programme
2. Workforce/Staff - Sites Leads and Facilitators delivering the programme
3. Patient (DWELL) Ambassadors
4. Training materials

The following methods were employed to collect Process Evaluation data:

- Focus groups with participants at the end of the programme
- Semi-structured interviews with staff and patient ambassadors
- Facilitator feedback following individual motivational interviews
- Participant Goal setting information during the programme
- Feedback from staff/ambassador training

For full details regarding the methodological and data analysis approaches of the process evaluation elements of the DWELL study, refer to Report 1: Methodology.

3. Context

Delivery of the 12-week programme took place across five sites: two sites in the UK and one site each in Belgium, France and the Netherlands. Each site delivered the programme according to their specific context (case study details of each delivery site are presented in Report 1). Sites were operating under different national and regional health care systems, differing guidelines for the care of people with type 2 diabetes, and also varied in workforce and venue capacity and resources (Table 1).

Table 1. National and regional health care contexts of delivery sites

				
HEALTH CARE PROVISION	**Funded from general taxation, providing universal access, which is free at the point of use. Devolved responsibility in the four nations of the UK (European Commission, 2019d)**	**Funded through either compulsory or voluntary health insurance which covers 95% of population and based mainly on a social health insurance (SHI), with a traditionally strong role for the state (European Commission, 2019b)**	**A mix of government mandated insurance for curative care, with additional premiums covering services outside the main packages, a single payer system for long-term care and local tax-funded social care (European Commission, 2019c)**	**A mix of mandatory public health insurance augmented by private health insurance and individual cost-sharing arrangements. Health care system is federated, with nearly universal coverage (European Commission, 2019a)**
CURRENT HEALTH SITUATION	**60% of adults in England overweight or obese, which has led to many more people living with type 2 diabetes (Number of people with diabetes reaches 4.7 million | Diabetes UK, 2019). As with many behaviourally related health risks, results are affected by lower education or income (European Commission, 2019d)**	**Over one in seven adults was obese in 2017, up from one in ten in 2000. More than three in five people aged 65+ reported having at least one chronic condition. Large gaps in life expectancy by sex and socioeconomic status can be explained at least partly by differences in education level and living standards (European Commission, 2019b)**	**60% of the Netherlands is overweight. Obesity has increased from 10% in 2000 to 13% in 2017. Wide disparities in health care exist in prevalence by education level, with people with the lowest level of education are nearly three times as likely to live with diabetes (European Commission, 2019c)**	**One in six adults obese in 2018, up from one in eight adults in 2001. Health continues to be affected by inequalities, large disparities in unmet medical care needs by income group and education (European Commission, 2019a)**

				
PREVALENCE OF DIABETES	10% of people over 40 living with a diagnosis of type 2 diabetes, approx. 3.42 million people in total. Thought to be almost 1 million more people living with type 2 diabetes who remain undiagnosed. By 2030 it is predicted the total number of people with type 2 diabetes in the UK will rise to 5.5 million. 4.3% potentially preventable admissions due to diabetes (Potentially preventable emergency admissions | The Nuffield Trust, 2017)	8% prevalence in 2016 (WHO, 2016b). Morbidity linked to diabetes has steadily increased since 2000 (Chevreul et al., 2015). With hospital admission rates for diabetes almost 20% higher than EU average (European Commission, 2019b). Avoidable hospital admission rates not available (Chevreul et al., 2015)	6.1% prevalence of diabetes (WHO, 2016a) with just over 1 million of the total population currently have a form of diabetes (Raaijmakers, 2014). Avoidable admissions for diabetes are among the lowest in the EU (European Commission, 2019c)	Exact number of people with diabetes not known as no registration system. From available health insurance data, diabetes has an estimated prevalence of 6.1%. However, Belgian Health Examination Survey revealed a prevalence of 10%, indicating that one third of people with diabetes are not aware of it. Hospital admissions for diabetes has reduced over the past decade and are overall currently at the EU average level (Gerkens and Merkur, 2020)
DIABETES CARE PROVISION	Operational policies, strategies and action plans cover diabetes. Diabetes care is set out through NHS Diabetes Prevention Programme and PHE's Next Steps (NICE, 2018). A range of medicines, procedures, and basic technologies are available, with 90% of people with type 2 diabetes offered structured education, and 10.4% attending (Whicher, O'Neill and Holt, 2020). No specific details on diabetes registry or recent risk factor survey	Operational policies, strategies and action plans cover diabetes (WHO, 2016b). Social health insurance has developed disease management programmes and pathway guidance (Chevreul et al., 2015). Metformin and insulin available, but no specific data is available on basic technologies. No diabetes registry or recent risk factor survey (World Health Organization, 2016b)	Operational policies, strategies, action and monitoring plans for diabetes and evidence-based national diabetes guidelines/protocols/ standards (European Commission, 2017). Nationwide Diabetes registry. No national risk factor survey. Insulin, Metformin and Sulphonylurea available. Range of basic technologies and more complex procedures available (European Commission, 2019c)	Operational policies, strategies and action plans which cover diabetes. With specific diabetes new care pathways (WHO, 2016). Evidence-based national diabetes guidelines/ protocols/standards and standard criteria for referral. Medicines available include insulin, metformin. Range of procedures and basic technologies (European Commission, 2019a). As of 2016 it does not include diabetes registry or recent national risk survey (WHO, 2016)
FUNDING OF DIABETES SERVICES	Average of EUR 2,900 per person compared to the EU average EUR 2,884. Expenditure is considerably lower than similarly wealthy EU countries such as Germany (EUR 4,300 per capita) and France (EUR 3,626. Spending has been relatively stable over time, but it has not kept pace with growing demand for health services (European Commission, 2019d). 10% of NHS entire budget on diabetes, 80% of this is spent treating complications (Whicher, O'Neill and Holt, 2020)	EUR 3,626 per capita on health, 25 % more than the EU average, sixth overall. Spending has increased from 10.3 % in 2007 to 11.3 % in 2017. Spending on prevention accounted for less than 2% of all health spending, a share lower than the 3.1 % EU average. Private voluntary insurance plays an important role in France, accounting for about 7 % of total spending (compared to less than 4 % in the EU) (European Commission, 2019b)	EUR 3,791 per person. The Netherlands is the fourth highest spender on health care per capita in the EU with 10.1% of GDP devoted to health. 3% health spending on prevention (European Commission, 2019c)	EUR 3,554 in 2017. 20% more than in the EU as a whole (EUR 2,884) but less than in all its neighbouring countries. 10.3% of its GDP on health in 2017, up from 8.9% in 2006. Disease prevention, allocating only 2.2% (European Commission, 2019a)

4. Implementation

Each site delivered similar core content in relation to the four main areas of DWELL – education, nutrition, physical activity and wellbeing. However, the implementation of the programme varied at different sites due to the national and regional context, as discussed in the previous section, and the varying resources and staff capacity across sites. For example, some sites had kitchen facilities and were therefore better equipped to deliver nutrition workshops and provide 'hands-on' experience for participants. There were also site-specific challenges experienced in terms of venue sourcing, timetabling and availability, which added to the administrative burden of delivery teams. This section explores further how the DWELL programme was implemented across the sites. Detailed information about the 12-week programme can be in the booklet 'DWELL Diabetes & Wellbeing' (Vanbosseghem, Callens and Luyens, 2020).

4.1 Participants

Evaluation data in relation to implementation and mechanisms was collected via end-of-programme focus groups with programme participants and interviews with staff (site leads and facilitators) and programme ambassadors.
Fifty-six focus groups were conducted across the five DWELL sites. Of the 274 participants, the majority were from the two UK sites where a higher number of cohorts ran. Focus group data collection took place in various ways per site. In the UK, focus groups were taking place at the final week of the programme so most participants were able to attend. In France, participants were invited in the focus group following the end of the programme and, for some cohorts, no focus groups took place, which accounts for a lower proportion of focus group compared to programme participants. In Belgium, there was a small number of cohorts, and only one focus group of 6 participants (first cohort) took place. In Netherlands, the delivery of the programme was on an individual basis, therefore feedback was relayed to motivational interview facilitators by individual participants (n=22). This was incorporated into the write up of the analysis, where feasible, to enhance points made, but was not included in the overall total of participants as the data was not collected via a focus group.
Nineteen of these focus groups, involving 65 participants, were conducted with cohorts which ran after March 2020 (when COVID-19 started). Twelve focus groups at UK sites (UK1 = 9; UK2 = 3) and seven in France. There were no post-COVID focus groups in Belgium or the Netherlands as these sites were not able to resume delivery of the programme following the easing of lockdown restrictions. This data was analysed alongside the original focus group data, and in most cases, the themes reported below relate to the full sample of focus group participants (i.e. from 2018 to 2022). Where there are differences between pre- and post-COVID data, this is noted.

Table 2. End-of-programme Focus Groups per site

Site	No. of focus groups	No. of focus group participants
UK 1	23	112
UK 2	20	95
France	10	50
Belgium	2	11
Netherlands	1	6
Total	**56**	**274**

Across the sites, 15 semi-structured interviews with site leads and 30 interviews with facilitators working in the programme were conducted. Depending on available resources per site, there were some variation to this data collection. For example, in France, a focus group with 4 facilitators instead of individual interviews was conducted, whereas, in Netherlands, feedback received from 13 facilitators was gathered via group interviews or email, especially with those who were involved in the programme to a lesser degree.

Table 3. Site Lead and Facilitator Interviews per site

Site	Site Lead Interviews	Facilitator Interviews	TOTAL
UK 1	3	7	10
UK 2	3	3	6
France	2	5	7
Belgium	3	2	5
Netherlands	3	13	16
Total	**15**	**30**	**45**

Table 4. Demographic profile of DWELL Ambassador interviewees

	DWELL Ambassador interviewees (N = 18)
Age (years)	Mean: 57.33
Age Band	< 19 years: -
	19 – 30 years: -
	30 – 39 years: 1 (5.6%)
	40 – 49 years: 3 (16.7%)
	50 – 59 years: 5 (27.8%)
	60 – 69 years: 8 (44.4%)
	70 – 79 years: 1 (5.6%)
	> 80 years: -
Gender	Male: 12 (67%) Female: 6 (33%)
Time since diagnosis	Mean: 11.29 years

4.2 Motivation to attend the programme

4.2.1 Better management of condition

Most of participants who provided feedback at the end of the 12-week programme were keen to make positive changes in order to manage better their type 2 diabetes and overall health. They were compelled to join the DWELL programme due to lack of knowledge and self-efficacy, the reasons for which included receiving little information or guidance from GPs and healthcare professionals. Some participants reported a sense of being treated with medication for symptoms but otherwise being abandoned, "left to get on with it" or being expected to know what to do themselves:

> *"After my diagnosis, my GP just gave me a prescription for medication. I received almost no information"* [Belgium participant]

Participants therefore entered the DWELL programme with differing personal models of diabetes, which were not necessarily accurate nor, in many instances, aligned with the medical view of the condition, which created a sense of frustration. Another reason behind participants' lack of knowledge was inconsistent and contradictory messages from different sources.

The most common areas where further knowledge was required were in relation to blood glucose, nutrition, medication, long-term health implications and complications, lifestyle changes, reversal of the condition, and wellbeing. There was a strong sense that participants wanted to take control of the condition and their overall health. Many reported complacency, struggle or despondency with doing so before attending DWELL:

> *"Even if we pay attention, our measurements* [weight, blood sugar] *go up and down, and that's what really hurts"* [France participant]

A smaller number of reports were made in relation to wanting to reduce or stop medication, or to prevent having to start taking it. These factors suggest that participants had intrinsic reasons for attending the DWELL programme, and before attending they tended to take a more passive role in their illness.

4.2.2 Experiences of negativity

UK participants in particular reported negative reactions from healthcare professionals in relation to their type 2 diabetes, often feeling chastised, dismissed or not being given enough time:

> *"With the diabetic nurse/at the surgery you don't get the time to go through things in detail - you're in and out"* [UK 2 participant]

Perhaps due to their personal representations, models and beliefs about type 2 diabetes, other participants reported that their diagnosis evoked fear and shock, as well as shame and overwhelm, whilst others reported denial or avoidance in addressing their diabetes:

> *"It was more of a shock to me to be diagnosed with type 2 diabetes than it was when I was told I had cancer…with diabetes, I felt guilty that I had put myself there, and it is now all my responsibility to take action for that."* [UK 1 participant]

4.2.3 Referral routes to the programme

The most common route was via a healthcare professional, including diabetic nurse, GP, dietitian and facilitators of other education programmes.. The next most common referral route was through programme advertising, i.e. participants seeing promotional materials, including leaflets and posters in GP surgeries, community pharmacies and other healthcare settings;, information stands in local libraries; advertisements in local press; and, social media e.g. Facebook, Twitter etc. Many participants were encouraged to join the programme by 'word of mouth' recommendations of those who had completed DWELL.

4.2.4 Meeting others with diabetes

Wanting to meet others who have type 2 diabetes or be part of a group was evident in feedback from participants and emerged more clearly in focus groups conducted after the pandemic, likely due to the fact that people had experienced social distancing and isolation and were more in need of company:

> *"To meet other diabetic people, to have an opinion different from mine"* [France participant]

> *"It's for the group because we are better able to work on our issues with exchanges, this allows us to put a number of things into perspective"* [France participant]

4.3 Facilitating factors

Participants were asked which elements of the DWELL programme they felt worked well. This section presents the most common themes in relation to these facilitating factors.

4.3.1 'Pick and mix' and experiential content

Participants reported that the four areas of DWELL – education, nutrition, physical activity and wellbeing – were well linked in each of the delivery sites. Higher engagement and enthusiasm was apparent where sites were able to incorporate these elements to a higher degree. For example, all sites provided sessions regarding nutrition, which were felt to be very valuable in clarifying misunderstandings and improving health literacy. Furthermore, Belgium, UK 1 and France sites had kitchen facilities available, enabling participants to be physically involved via hands-on cooking sessions. The opportunities to learn new skills, try new food, cook recipes, learn about alternative ingredients and satiety, and eat together at the end of the session were well received by participants, which was also noticed by staff:

> *"It inspired you and made you want to cook. It was surprising how quick easy it was to prepare lovely food."* [UK 1 participant]

> *"They're having fun, getting stuck in with cooking stuff, and it tastes good…it's the flip side of the 'you can't eat this, you can eat that."* [DWELL team member, UK 2]

4.3.2 Flexible programme delivery

Participants commented favourably on the programme set up, particularly in group size and course duration. Keeping group size small was conducive open communication, as well as group bonding and interaction, which are protective factors to health (Marmot and Bell, 2012):

> *"I think the small group size* [6] *is key…we have talked to and encouraged each other, built relationships…I like the flexibility of the sessions and that I can listen to other people and find out what their experiences are."* [UK 2 participant]

It was also important to participants in all sites that evening sessions were available:
"I couldn't believe there was something I could attend that wasn't during the day…I never expected that. So, when it did, even though it was a big commitment…I had to come on it." [UK 2 participant]
Staff reported that the environment played a part in the effectiveness of the programme. A welcoming, informal venue was preferred, and those sites that delivered DWELL in non-medical setting felt that this helped to reduce or overcome barriers and promoted communication exchange:

> *"As DWELL takes place outside of the hospital environment, it removes certain barriers that may exist between caregiver and patient - there is a social bond and friendships are created… people stay connected."* [DWELL team member, France]

A theme that emerged in 'post-COVID' focus groups was flexibility, particularly around attendance of the programme. Several participants had work or family commitments or travel issues and appreciated being given the opportunity to join some sessions via video link, which is something that was only made available as a result of COVID when delivery sites were required to develop new virtual ways of working.

4.4 Challenges and improvements during implementation

Participants were asked which elements of the DWELL programme they felt did not work well and were invited to suggest improvements. This feedback was passed anonymously to the delivery teams who used it to further shape and enhance the programme.

4.4.1 Content 'outside of comfort zone'

The element of the programme which received the most feedback were the wellbeing sessions, which included sessions such as self-care, guided conversations, creative activities, mindful walks, body image, singing and ukulele playing. Some programme participants found sessions to be "outside of their comfort zone" initially. However, despite initial reluctance, there were numerous comments made in relation to making the link between mental and physical health, which was also noticed by staff:

> *"I didn't appreciate how stress could affect your HbA1c…you push it aside and you carry on, until you come to something like this programme, and it starts to ring bells…stress catches up with you."* [UK 2 participant]

> *"I think the wellbeing element is really working...For some participants it was a bit difficult to see their talents on their own, but many later mentioned that they had not looked at or thought about it in this way. They ended up feeling more able to take a holistic approach to their T2DM and mechanisms for coping with it."* [DWELL team member, Belgium]

There were suggestions made as to how the wellbeing element could be improved, including a better explanation at the outset as to its importance and links with type 2 diabetes, management of expectations, and making it one of the optional 'pick and mix' offerings after an initial introduction, for those that were more interested.
Another critique of the DWELL programme was that the physical activity element was not as prominent as anticipated, particularly in the UK sites. At sites where physical activity was incorporated as part of the programme it was motivating:

> *"Walking, yes that helped me a lot…socialising and walking. It helped me to be with other people, to go for a walk, to be in a group. I am very happy with that…Sport on my own I wouldn't have been there. Together, that motivates me."* [France participant]

Suggestions from participants included incorporating physical activity into the programme and tailoring it to different levels and abilities, for example having optional time at the end of each session for a walking group for those that participants that were interested. Another suggestion was the provision of free or subsidised local gym memberships for the duration of the programme to improve access for participants.

4.4.2 Operational and logistical barriers

Most participants felt well equipped to sustain their progress at the end of the programme. The follow-up evaluation assessment at 6 and 12 months was perceived as a useful incentive to keep up with positive changes they had achieved. Some felt concerned about sustaining progress after the end of the programme and felt it would be beneficial to be provided with ongoing sources of support by the sites. Similar feedback was given by participants who undertook the programme after the COVID-19 lockdown restrictions eased, especially as they did not have regular access to healthcare appointments, professionals and education during lockdown and valued support received through DWELL. Suggested follow-up could be regularly (weekly or monthly) or maintaining contact with and have ad-hoc support by staff.
Overall, participants across the sites felt that the timing and duration of sessions were appropriate. There was some feedback that was taken on board by sites and adaptations were made. For example, early programme cohorts reported daytime delivery as a barrier for those in full-time employment who either found it difficult or impossible to attend sessions. As a result, programme leads and facilitators added the option of joining an evening group, which proved a popular choice. Feedback was also received about programme sessions running two consecutive days per week in some sites, which was felt to be a major time commitment for participants; this consideration led to adjustments.
From the perspective of DWELL staff, the main operational challenges were in terms of resources and recruitment. Resource issues included staff turnover, availability of external facilitators, running costs and suitable venues. Recruitment was challenging in a variety of ways, such as engaging with primary care professionals to refer people to the programme, assessing suitability of potential participants and time constraints (which linked back to available resources).
During the project lifetime, staff refined and shaped the programme in response to participant feedback. Changes made included:

- **Facilitation** - introducing new experts to run sessions, replacing staff who left the project, main facilitators covering sessions when external providers were no longer able to do so
- **Content** - adding or amending activities based on participant feedback, adding further 'pick and mix' activity

options
- **Timing** – implementing evening sessions, adjusting the duration of sessions, staggering dates of cohorts to allow for recruitment activities
- **Recruitment** – developing new strategies to recruit to the programme
- **Resources** – adjusting staff hours, sourcing new venues, amending materials in line with facilitator and participant feedback
- **Attendance** - allowing partners of participants to attend sessions alongside them for support.

4.5 DWELL and other educational programmes for diabetes

Participants reported that DWELL compared favourably to other educational programmes they had attended in relation to type 2 diabetes. The main reasons for this positive feedback included that the smaller group size, longer duration and level of detail of DWELL. Skinner and Cradock (2000) suggest that if information provided is too generic, it can be rationalised by the participant as not relevant. However, in the DWELL programme, dual process theory was employed whereby individuals were involved in the learning process as much as possible and given the opportunity to ask questions, gain clarity and have ample time assimilated and retain learning.

> "[On the other course] *we were bombarded with four hours of information…I don't remember coming away with the don't eat carbs, as you do with DWELL. It was too much information all at once, and you didn't have time to ask any questions."* [UK 1 participant]

The delivery style of DWELL was also preferred compared to other programmes:

> "[The other programme] *was like being in school again…just sitting there listening and you're too scared to ask anything"* [UK 2 participant]

4.6 COVID-related challenges

In March 2020, the 12-week programme delivery was paused across all sites due to the COVID-19 pandemic, interrupting ongoing cohorts. When delivery resumed, following the easing of lockdown restrictions, the subject of the impact of COVID-19 and its impact came up naturally in end-of-programme focus groups. The themes that arose highlight valuable points for consideration, not just for DWELL but for similar psychoeducational programmes which focus on long-term health conditions.

The general consensus was that the pandemic had resulted in diminished self-efficacy, i.e. the ability of participants to enact the lifestyle behaviours learnt during DWELL and follow through on their action plans due to being more sedentary, becoming unwell with COVID and the mental strain of social distancing, isolation and long periods of lockdown. Access to health services was an additional challenge experienced during lockdown; programme participants were reluctant to visit their GP for their HbA1c tests or other issues due to the risk of exposure to the virus. Also, participants experienced challenges in relation to nutrition, e.g. not being able to access certain ingredients or not being able to visit shops.

Some participants chose not to put themselves under undue pressure, with a view to getting back on track at a later date. There was a sense of confidence that they would be able to continue with the lifestyle changes and progress they had started to make:

> *"I've kind of backed off a little bit during lockdown, but I actually felt the strength of the programme is that I know I've learnt enough, then when it's back up it won't be a problem."* [UK 1 participant]

The challenges experienced by DWELL participants during the COVID-19 pandemic and lockdown align with Dahlgren and Whitehead's (1991) social determinants of health model, in that an individual's environmental, living, working and social conditions have a direct influence on health.

From the perspective of staff, challenges with recruitment continued post-pandemic. There was a lot of anxiety amongst participants to return to group settings and sites found it difficult to recruit to evening groups, especially given that the momentum they had built from 'word of mouth' recruitment had been lost during the pandemic. Group sizes therefore tended to be much smaller in post-COVID groups compared to before March 2020. However, facilitators noticed that participants flourished as the programmes continued and felt that the programme became even more effective, particularly for those who were more socially isolated. For example, in one group, an elderly male participant who lost his wife during lockdown was described by the facilitator as being at "rock bottom" when they joined the group and felt very uncertain about attending the group as he had lost confidence. However, the facilitator noticed a big change in him as the programme progressed:

> *"He did come, and you could see his confidence building. One of others pointed out to him that*

at the start he didn't talk, and by the end he was one of the cheeky ones. He said it had been his first step back into doing things again...Without DWELL, I can't image how he would have achieved that." [DWELL Facilitator, UK 1]

4.7 Cross-border learning

Process evaluation highlighted commonalities and differences across the DWELL delivery sites and countries. In terms of common themes, all participants acknowledged as facilitating factors of the programme the following: strong peer support; experiential diabetes education (e.g., on-site cooking lessons); inclusive facilitation approach; motivational goal setting; and delivery flexibility (e.g., availability of evening sessions).

In terms of motivation for attending the programme, all participants noted that they had experienced absence of accessible information about type 2 diabetes. Also, most participants had previous negative feedback or attitudes about their management of the condition, especially in the UK, in terms of feeling dismissed or chastised by healthcare professionals and experiencing stigma or guilt about their condition, or they were given contradictory advice by professionals and service providers. Therefore, the main common motives were to have reliable information about diabetes and learn how to manage better their condition.

Key points from DWELL Implementation:

- Motivating factors for participants to engage with the programme were: better management of their diabetes; experiencing negativity such as stigma and feeling dismissed by healthcare providers; being referred to the programme by a healthcare professional; and wanting to meet others with the condition.
- The DWELL programme enhanced health literacy and self-efficacy of participants
- Programme set up was effective and flexible. Reported issues regarding content in relation to the wellbeing and physical elements were addressed by the teams. There were also some operational and logistical barriers such as lack of follow-up (for participants) and resources and recruitment (for staff). Adjustments by sites during the project included: facilitation; content; session timings; recruitment strategies; resources; and allowing partners of participants to attend sessions.
- The DWELL programme compared favourably to other educational programmes for type 2 diabetes that participants had previously attended.
- Differing contexts across countries and sites impacted on how the DWELL programme was implemented. The COVID-19 pandemic created challenges in implementation during that period, namely, substantial difficulty in recruiting participants to the programme and making changes to the set up and mode of delivery. However, for many participants, the DWELL programme provided the opportunity to maintain a sense of normality and interact with other participants in person after lockdown restrictions were lifted.

5. Mechanisms

Three of the main mechanisms utilised in the DWELL programme were peer support, motivational interviewing and goal setting.

5.1 Peer support

Peer support is defined as *"support from a person who has knowledge from their own experiences with diabetes, a person with diabetes, or a person affected by diabetes (eg, immediate family member or caregiver)"* (Litchman et al, 2019). Peers can provide ongoing support that is needed for sustained self-management of diabetes. Key functions of effective peer support include assistance in daily management, social and emotional support, linkage to clinical care, and ongoing availability of support (Fisher et al, 2012). Peer support, alongside other support, has been shown to help people learn to live with their condition, day-to-day, giving them the confidence, knowledge and support required to manage the complexities of living with a long-term-condition (NHS England, 2022). Group peer support as a DWELL mechanism was identified very strongly by programme participants, staff and ambassadors across all delivery sites. A sense of community was established through sharing problems and solutions, working together and motivating each other:

"Being a diabetic is extremely isolating. There's no-one round me that understands diabetes and I've had to go through it alone, which I've found very difficult. But I found being in a group of other like-minded people has helped enormously … we are sharing the experience of our diabetes, so instead of feeling like we're carrying this problem on our own, it's more a problem that we know other people are sharing." [UK 2 participant]

"The group element of the programme works very well and is massively powerful. You can see people support each other and motivate each other…from giving someone a lift to making sure if they are okay if they don't turn up to giving someone confidence who is feeling a bit insecure during the education session. Also in terms of feeding back and being accountable to each other." [DWELL team member, UK 1]

Participants enjoyed the others' company and maintained contact with each other between sessions via social media, email, WhatsApp groups and meeting up in-person:

> *"We had great meetings, and we are all very close together, so I liked it also to meet people … We all went to eat at the restaurant, simply, it was the fact of being together."* [France participant]

Also, participants were very positive about the supportive and inclusive approach of programme facilitators, involving them in the process, an important element which enhances understanding and leads to information being considered as relevant by the individual. For the facilitators, there was very much a sense of accompanying the participant on their journey:

> *"We are there together, we progress together. The notion of 'professionals' disappears and we are just companions."* [DWELL team member, France]

The introduction of DWELL Ambassadors was an additional strong peer support element. DWELL Ambassadors were 'peers', people with type 2 diabetes who were involved from the start of the project as 'experts-by-experience' in the co-design and delivery of the programme. Each DWELL Ambassador was involved in ways that suited their own preferences, skills and capacity, such as: providing feedback at the pilot of the programme; acting as ambassadors of the programme in national project meetings, events and conferences; promoting DWELL to others in the community; setting up programme social media accounts and producing newsletters; initiating and running activities in the DWELL programme. For example, in the UK, an Ambassador implemented a weekly craft group for DWELL participants, and, in France, Ambassadors attended sessions alongside participants and set up walking groups, which enabled further opportunities for support and connection:

> *"I had a good exchange with them* [Ambassadors]*, I talked with them about diabetes, the physical* [aspects]*, we talked with them about their motivation."* [France participant]

> *"I meet different people, whether at the walks or at the cooking workshop, and we have created a fairly intimate bond and the bond is very strong because we stay in contact even if we meet them walking 3 times a week…if they are sick we hear from them, if they are in difficulty they call us and we are there to inform them and give them good advice."* [DWELL Ambassador, France]

5.2 Motivational Interviewing

Motivational interviewing is a directive, person-centred counselling style for eliciting behaviour change by helping clients to explore and resolve ambivalence (Rollnick and Miller, 1995). The motivational interviews (MIs) were an innovative part of DWELL, and although previous studies involving people with type 2 diabetes tended to focus on feedback from participants receiving motivational interviews (Heinrich et al., 2010; Chen et al., 2012; Dellasega, Añel-Tiangco and Gabbay, 2012), the DWELL research team opted to elicit data and feedback from those facilitating the MIs. The main reason was to understand from the facilitators' point of view how the MI approach was applied and how MI principles impacted on participants' experiences of the programme.

At the end-of-programme focus groups, participants noted that they appreciated the tailored support offered by MIs, which allowed them to set and discuss goals at the start and end of the programme. The MI approach enabled facilitators to take a holistic view of individuals and consider wider issues they were facing in their lives which might be affecting their management of diabetes. Furthermore, MI discussions enabled participants to feel secure, be actively involved in the process decision making in relation to their health and empowered with the locus of control to set intrinsic personal goals:

"[The MI] *was probably one of the most valuable parts of the programme. It made me think better about my own process behind weight gain and eating … The facilitator has a good skill in getting to me and my own mental processes."* [UK 1 participant]

"We weren't told what to do, we were encouraged to decide for ourselves and given suggestions … That made us want to do it rather than feel like we had to." [UK 2 participant]

5.2.1 Application of MI principles in the DWELL programme

Four MI principles relate to 'positive framing' (establishing willingness to engage, expressing empathy, evoking intrinsic motivation, using affirmations), and two principles address negative participant behaviours (addressing ambivalence, adjusting to resistance). Figures 2 and 3 below demonstrate how frequently these MI principles were applied by facilitators at each delivery site, at the beginning and end of the programme.

At the beginning of the DWELL programme, the most frequently applied MI principle across all sites was 'establishing willingness to engage', followed by 'express empathy'. The least frequently applied MI principles at the start of the programme were 'addressing ambivalence' and 'adjusting to resistance', which were applied at broadly equal frequencies. Similarly, at the end of the programme, the most frequently applied MI principle was 'establishing willingness to engage', followed by 'using affirmation'. The least frequently used were again 'addressing ambivalence' and 'adjusting to resistance', although the latter was much less frequently applied at the end compared to the beginning of the programme.

The application of more positively framed principles aligns with the DWELL ethos of empowerment, peer support and the holistic approach.

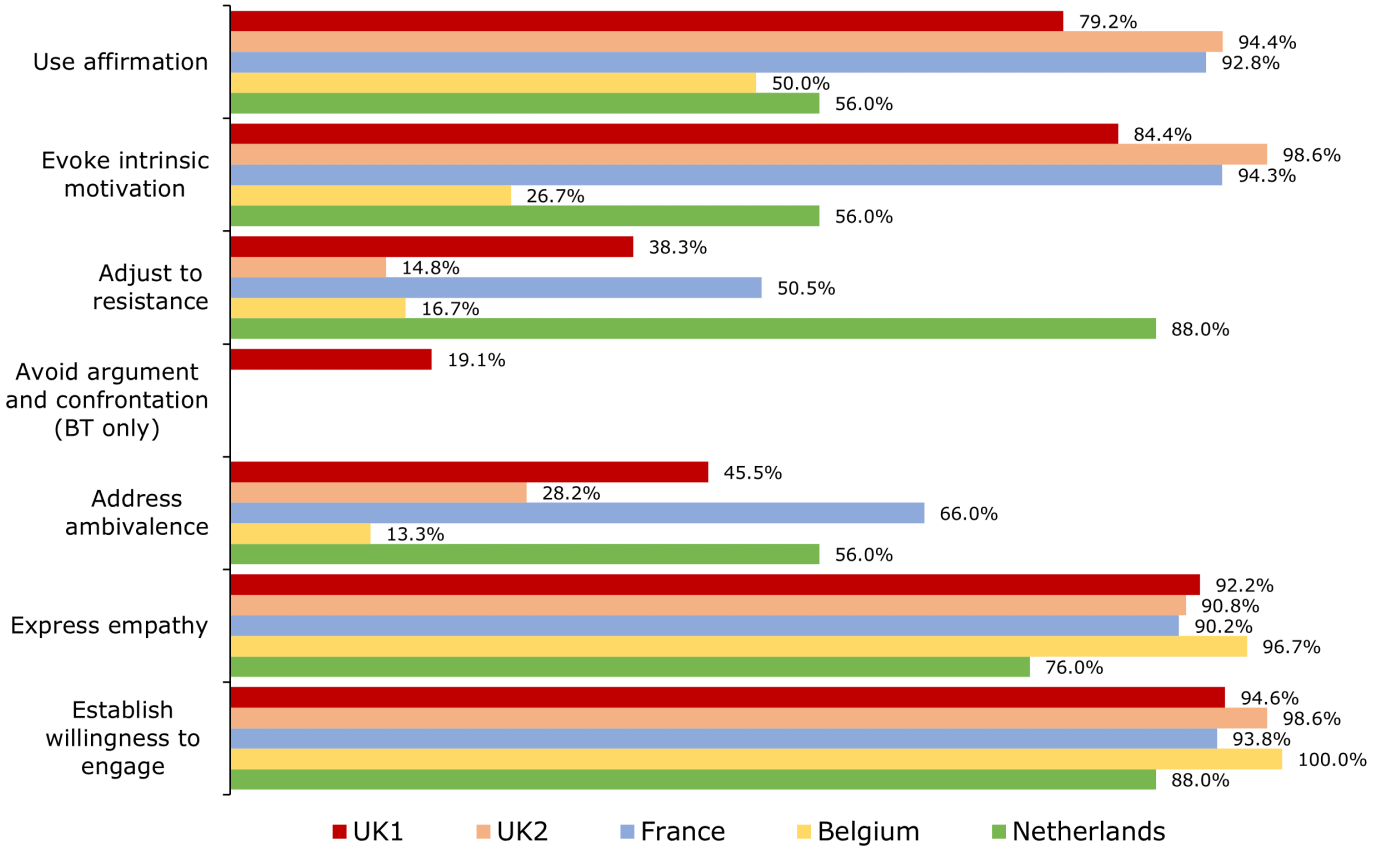


Figure 2. MI principles applied at the start of DWELL programme across sites

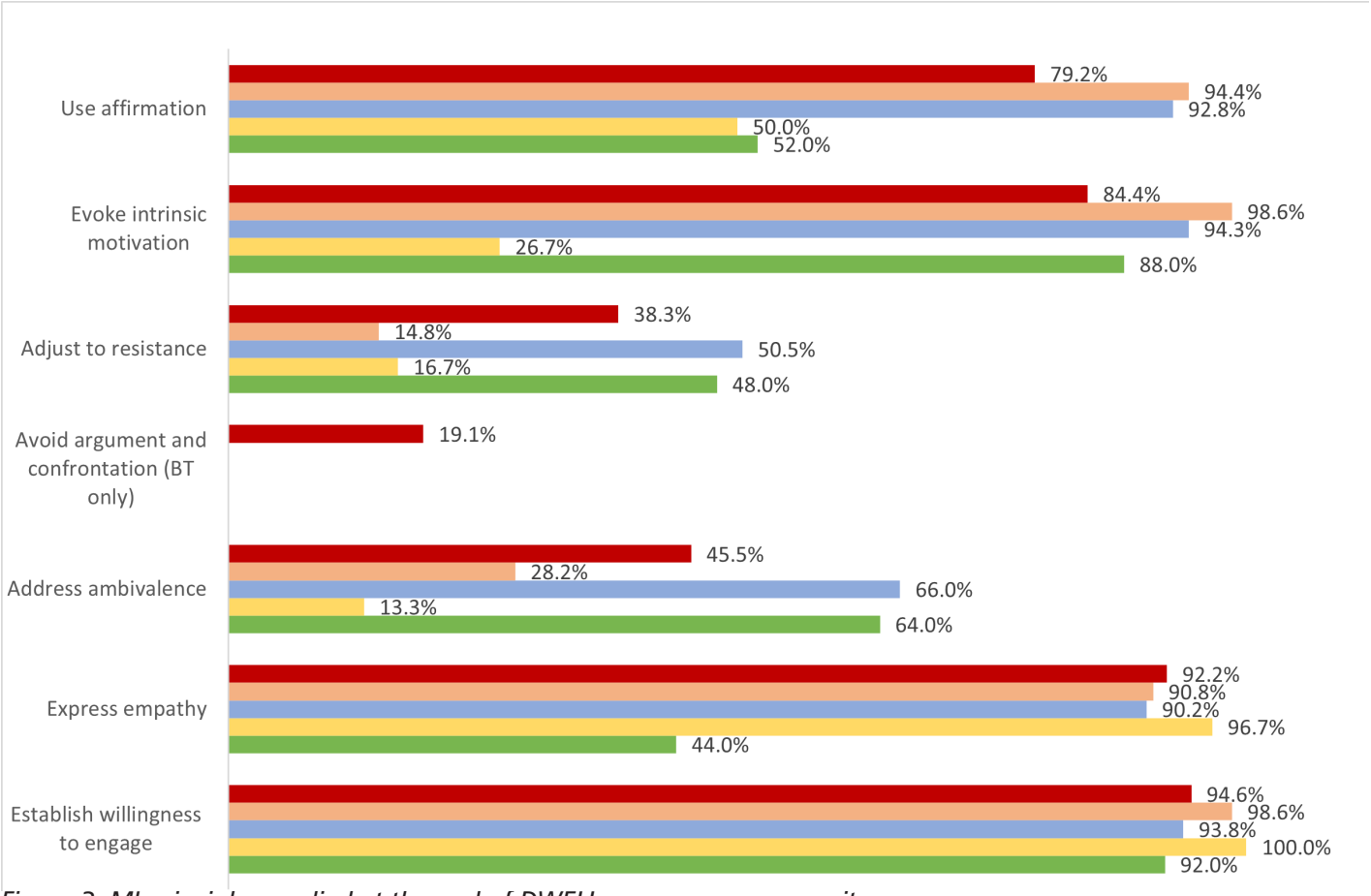


Figure 3. MI principles applied at the end of DWELL programme across sites

Further analysis of the MI data collected from facilitators uncovered how principles were effectively applied and their impact on the success of the participants, as the following vignettes highlight.

Using affirmations

Acknowledging and affirming progress, even in cases where the change in metabolic health as not to the degree the participant anticipated, was an important element of the MI process.

Vignette A

During their first MI, the participant told the facilitator about their personal issues, including a difficult background, recent bereavements, relationships with remaining family members, significant health challenges, and very limited mobility. The conversation uncovered a general feeling of isolation and lack of support. The participant was initially unwilling to change diet initially and was encouraged by the MI facilitator to attend the sessions if they felt they were able to.

At the second MI, although the participant felt that not much had changed, the facilitator highlighted that s/he had achieved much more than s/he realised, despite personal challenges. Achievements included setting feasible goals, making substantial dietary changes, and increasing levels of physical activity. The participant recognised s/he was finding it easier to meet new people and make friends, which was a huge step for them considering how socially isolated they felt at the start of the programme.

Despite the participant's early reservations about changes, s/he achieved weight loss (decreased by end of the programme from 201kg to 198kg and even further to 192kg 12 months later). Their HbA1c levels remained the same (69 mmol/mol) during the programme but reduced to 60 mmol/mol 12 months later. More importantly, the participant reported behavioural improvements - control over emotional eating had increased, with an above average increase in eating restraint. S/he also had a better understanding of their diabetes (above average) and their ability to predict the effects of their diabetes had also increased (above average).

Site: UK 1, cohort: 1

Addressing ambivalence and resistance

The MI feedback uncovered a variety of ways in which participants were resistant to change and how facilitators addressed ambivalence between goals and current behaviour, rather than opposing the situation directly. This process was managed through active listening as well as providing encouragement for what the participant could do or had already achieved.

Vignette B

The participant felt that s/he wanted to make changes but was experiencing resistance. The facilitator listened and asked them what benefits she might experience if she was to implement behaviour changes. In the lead up to the second MI, the participant had not attended some sessions and felt that perhaps the DWELL programme did not work for her. However, through applying MI principles the facilitator was able to affirm that the participant had already made a number of small behaviour changes that she had not recognised, which resulted in a positive outcome to the MI meeting.
Although the participant did not have metabolic measures taken nor did she complete the DWELL Tool at the end of the programme, the facilitator reflected on their progress and the impact of the MI:

"She said that she felt the programme had not resulted in any changes for her, but we discussed it further and she recognised that she had in fact made some big changes. She was now walking three times a week, which she was not doing before DWELL. Furthermore, she had been walking with a friend after learning in the session that social context is important. Following that session, she had called friends to set up a regular weekly walk with them."

Site: Belgium, cohort: 1

5.2.2. Overcoming challenges during motivational interviewing

The MI data uncovered some of the challenges faced by facilitators in eliciting behaviour change, including participants becoming defensive when questioned or not being ready or willing to open up about their issues. There was a sense that, for some participants, a 12-week programme was not long enough to unpick and address longstanding issues. However, there were often numerous positive changes noted between the start and end of the programme, despite initial challenges.

Vignette C

Despite a long conversation, the facilitator found it difficult to obtain a sense of this participant's motivation as they would regularly digress. However, through applying the MI principles, including expressing empathy and addressing ambivalence, the facilitator was able to deduce a number of things - the participant had experienced cultural displacement in moving to the UK, they did not like to think about stressful things (including their health), they felt they received very little support for their diabetes, and had ingrained habits around food (such as eating rice at most mealtimes and being unable to resist sweets).

By the second MI, the participant reported significant dietary changes, including giving up rice almost entirely, after years feeling convinced that they needed it. Additionally, they had set new goals – to sustain their progress and to lose weight slowly. The participant described DWELL as *"epic"*, and the improvement of their physiological measurements further highlights the progress they made despite their initial challenges. Their HbA1c levels reduced from 64 mmol/mol to 54 mmol/mol and reported significant illness perception changes - reduction (above average) in the time they felt their condition would last and in feelings that their condition would have negative life consequences. They also felt better able to predict development of their condition, had better personal control, control of their treatment, more restraint in terms of external food cues, and felt also more able to understand their condition.

Site: UK 1, cohort: 2

5.3 Goal setting

Goal setting was another mechanism employed during the 12-week DWELL programme to encourage participants to focus on making lifestyle and behaviour changes to enhance empowerment and self-management of their type 2

diabetes.
All delivery sites captured goal setting at the beginning of the programme, with some sites adding additional time points (e.g. weekly or mid-point goals). Therefore, reported goal setting refers to the beginning of the programme. Goals were initially coded and classified into sub-themes from which four main overarching themes were formed (Figure 4). A table containing the full list of initial codes can be found in Appendix 1.

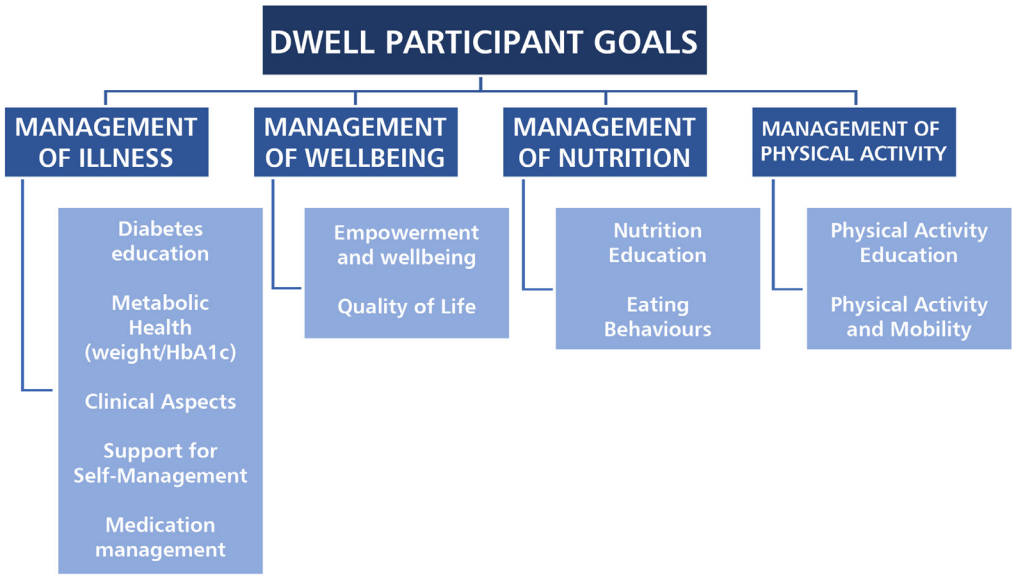


Figure 4. Key areas of Goal Setting at the start of the programme across all sites

The most common types of goals set were in relation to overall Management of Illness, and the least common were in relation to Management of Physical Activity. Further analysis of the broad themes showed that participants focussed on specific areas such as improving metabolic health, diabetes education, maintaining or increasing physical activity/mobility, obtaining education about nutrition and enhancing empowerment and wellbeing. Figures 5 and 6 show that themes and sub-themes of goals set by participants across all sites at the start of the 12-week programme.

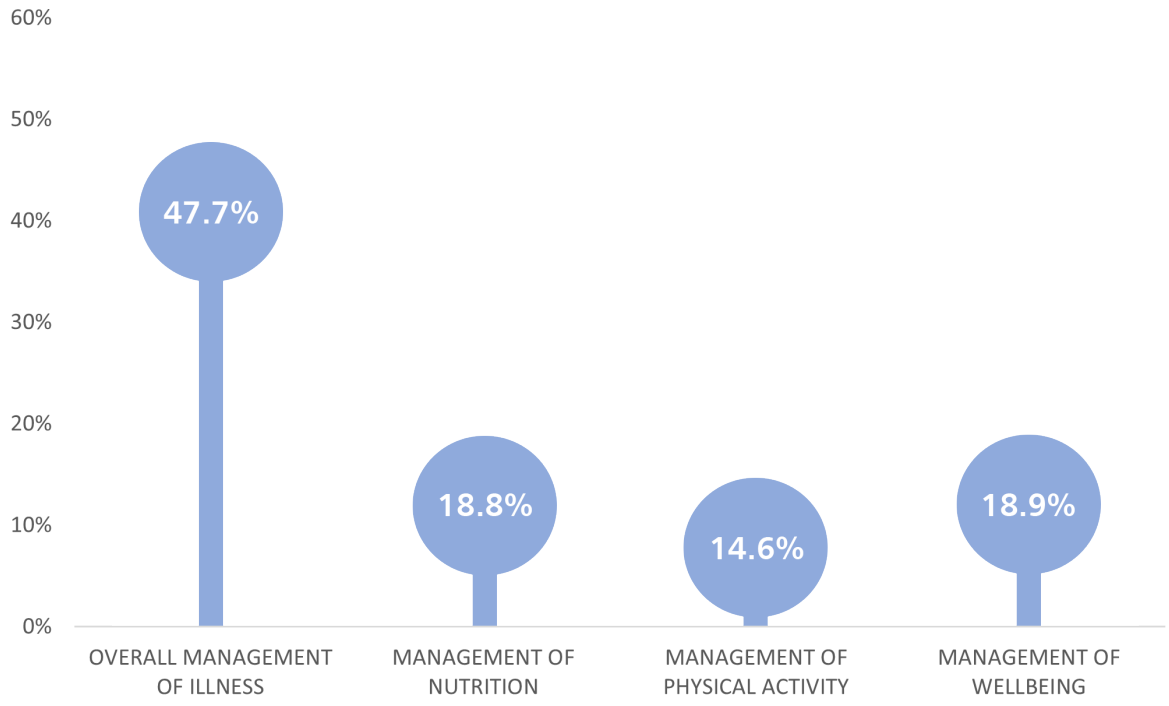


Figure 5. Participant Goal themes across sites

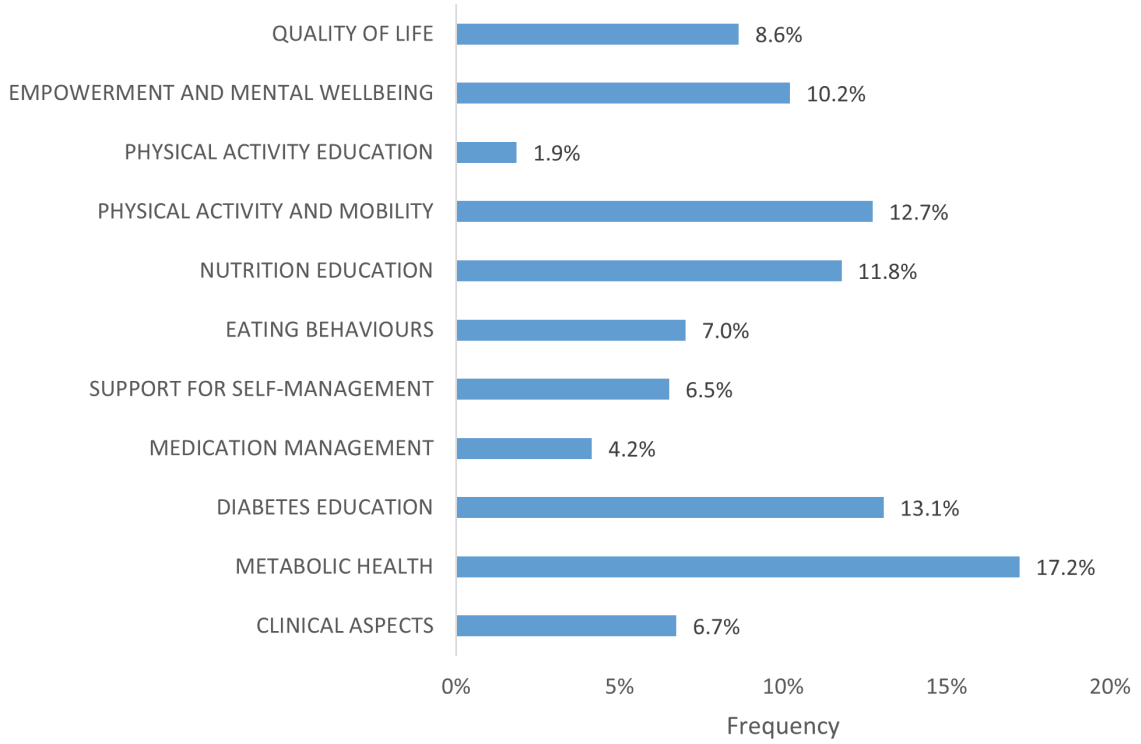


Figure 6. Participant Goal sub-themes across sites

6. Outcomes

The qualitative findings in relation to programme outcomes in this section should be read in conjunction with Report 3 'Participant Outcomes', which presents the results of the outcome measures collected by the 'DWELL Tool' questionnaire at four different time points.

Key Points from DWELL Mechanisms

- DWELL incorporated key mechanisms to facilitate empowerment and better self-management of participants: peer support, motivational interviewing (MI) and goal setting
- The effectiveness of peer support came out very strongly in both the focus group and interview data across all delivery sites. A sense of community was established through facilitators ambassadors and participants sharing problems and solutions, working together and motivating each other
- The most applied MI principle was establishing willingness to engage in the programme
- DWELL Participant Goals had four overarching themes: Management of Illness, Management of Nutrition, Management of Physical Activity and Management of Wellbeing
- Goals set by majority of participants across all sites at the start of the 12-week programme were in relation to Management of Illness
- Five particular goals participants identified were: Metabolic Health, Diabetes Education, Physical Activity and Mobility, Nutrition Education and Empowerment and Mental Wellbeing

6.1 Enhanced self-management of diabetes and health literacy

Many participants had little knowledge about type 2 diabetes prior to joining the DWELL programme. Through the course of the 12 weeks, their improved knowledge led to enhanced self-efficacy and improved illness beliefs, as illustrated by the below quotes from end-of-programme focus groups:

> *"There have been so many lightbulb moments, where I have thought 'I understand why that is happening now'."* [UK 1 participant]

"What I've come out of it with is an understanding of really how it all works…how different things affect me and what I can do to counter that. And so I know that if I've been 'bad', I know why it is having the effect it is having." [UK 1 participant]

Commonly reported as newfound/improved knowledge by participants was also in relation to nutrition, namely the effect of carbohydrates on blood glucose levels:

"All the advice I was given previously was to stop eating sweets. So, I never knew how important the carbs were because I was a carb lover…I thought diabetes was just only to do with sugar." [UK 2 participant]

Participants also reported better medication management, having not previously fully understood how it was helping them, when and how to take it:

"I'm now getting up early. I used to feel lazy in the mornings – I didn't want to get up for work, didn't want to get up for anything. But changing the times I take my medication, as advised by the facilitator…and probably the food I'm now eating…has made a difference to my energy…I get up before the alarm now." [UK 1 participant]

"I have got a better relationship with the way I use insulin now…I now understand how it works in my body and what it's there for…realising the impact of carbs on insulin and how much you should be using and at what times has really helped…therefore I am not feeling as rough as I used to. I used to feel quite poorly sometimes as my blood sugar was swinging one way and the other. In the mornings, I was getting up and it was 18-20, but through the education side of [DWELL]*, well this morning I was 10.4. A combination of everything we have learnt on this course has really worked for me"* [UK 1 participant]

The MI data collected from DWELL facilitators also highlighted the improved health literacy of participants.

Vignette D

At the start of the DWELL programme, this participant was on the waiting list for bariatric surgery due to ongoing struggles to keep their weight at a healthy level. They were feeling unsure about going ahead with the surgery, but felt it was their last resort. During DWELL, they set a variety of weekly goals, including keeping a food diary, checking food labels, reducing food portion sizes, implementing mindful breathing exercises and making time for themselves.

By the end of the programme, the participant was feeling much more knowledgeable about their diabetes and the factors that impacted on it. They felt much more in control and had made a lot of progress. Their weight and BMI decreased slightly, their waist circumference reduced from 147cm to 137cm, and their HbA1c decreased from 74.7 mmol/mol to 58.8 mmol/mol. They reported having made good friends through the programme, their relationship with their partner had improved and, importantly, they felt empowered to make the decision not to go through with the bariatric surgery due to the progress they had made on their own.

There was also a notable increase in empowerment, control over eating when dealing with emotional and external eating cues, and increased eating restraint behaviour in terms of managing their diet.

Site: UK 2, cohort: 6

6.2 Making lifestyle changes

DWELL participants reported significant lifestyle changes due to their learning in the programme. There was an overall sense that participants had realised through the DWELL programme that they needed to maintain long-term lifestyle changes, rather than "quick fix" attempts, such as strict diet plans:

"The course helped me to realise that I had to live in another way and that I need to change my life or to adapt some of the things in my life." [Belgium participant]

For example, following nutrition sessions, participants reported learning about alternative ingredients, portion sizes, new recipes and cooking with fresh ingredients. This led to greater awareness and improved behaviours in terms of food shopping and the ability to make positive, informed choices:

"Since starting DWELL my diet has changed almost completely. I look at everything we eat now. I feel that I have got more energy as a result." [UK 2 participant]

"Prior to coming on this course, I probably pretty much lived on ready meals…The education made me realise how bad they are for diabetics, and I now know it is possible to make nice food for yourself……I feel more confident about cooking, which is a complete sea change for me." [UK 1 participant]

Also, participants reported new healthy behaviours in terms of physical activity levels after attending programme sessions. Increased awareness regarding the benefits of being active on their diabetes led to participants finding ways to be less sedentary and starting or returning to regular movement, in particular walking:

"Although I am not usually one to exercise, I am now trying...I now walk up the stairs to my flat…I can go right up to my floor now without stopping on the landings…I am using a floor cycle…I have been into town on my own on the bus, which I hadn't done for two years. I'm setting goals for myself, like walking back from the group." [UK 1 participant]

6.3 Enhanced wellbeing

During the programme, participants learnt about the relationship between mental health and diabetes. They were introduced to tools and techniques to manage emotions and stress which they could maintain on their own at home, such as mindfulness, meditation, breathing exercises and music.
Most participants reported feeling empowered in general, as well as in relation to their management of diabetes. Improved health literacy led to greater autonomy in making decisions about their health. For example, participants felt able to initiate discussions with their physician/GP:

"I have learnt more in the last 12 weeks than I have in the 15 years since my diagnosis. And I have taken control…I have told my GP what tests I want, and I know that I am entitled to them, and have been able to discuss and take control of my medication as well." [UK 1 participant]

"You have to take charge yourself. You shouldn't rely too much on others. You are given tools to work with, then it's up to you to sharpen the tools to make them last a long time." [France participant]

One of many examples of improved self-care is highlighted by a quote from a participant who had started setting boundaries with others and taking time to look after themselves:

"It taught me that I matter…I have continued to take the afternoons I was attending DWELL as my own time. I do arts and crafts, go for a walk, watch a film or read a book. When you take control of your life and doing things that are positive, you've got a handle, you've got control." [UK 2 participant]

The DWELL programme also gave participants a more positive perspective, including more acceptance of their condition, increased motivation and energy, less fear, and more hope and confidence for the future:

"It's given me hope. Hope that I can reduce my medication and I can possibly even reverse the condition, whereas before I didn't think it was possible." [UK 1 participant]

The MI feedback by facilitators also highlighted improvements experienced by participants in relation to wellbeing, including enhanced empowerment and self-care.

Vignette E

At the initial MI, the participant shared a sense of a loss of control, not just in terms of diabetes but with life in general. The facilitator expressed empathy about the participant's caring responsibilities, which resulted in them having little time to focus on themselves and their own health. The participant's perception of being the only person who was able to undertake the caring role of a family member was uncovered, and there was a sense of feeling overwhelmed. The participant initially showed resistance to making lifestyle and behaviour changes - ***"There's no point. I have these other commitments and there's nothing I can do about them".***

The facilitator suggested that the participant could focus on small and simple goals initially and build on them. At the second MI, the participant was very pleased with their results and reported having more energy and focus, as well as having put new boundaries in place in order to look after themselves better - ***"My Tuesday and Wednesday afternoons are for me now…I'm getting up an hour earlier each day…Even though I have the same responsibilities as before, I am handling them much better."***

The participant's weight had decreased from 130kg to 117.9kg, waist circumference had gone from 137cm to 128.5cm, and HbA1c was down from 61 mmol/mol to 51 mmol/mol. Six months after the DWELL programme, the participant's metabolic health had further improved (weight was down a further 4kg, waist circumference down 5cm, and HbA1c had reduced to 42.7 mmol/mol, which put them into the pre-diabetic range (42-47 mmol/mol).

These changes were also reflected in self-perceptions and behaviours – there was a notable decrease in perceived negative consequences of their diabetes and in the length of time they anticipated their diabetes would last. Furthermore, they felt much more able to predict their illness, had increased feelings of control in relation to external eating cues, personal control, control of their treatment, understanding of their illness and empowerment.

Site: UK 1, cohort: 1

DWELL Ambassadors also reported enhanced wellbeing as a result of their involvement in the project, for example through finding fulfilment and purpose, and empowerment through being part of conversations with healthcare professionals and experts in the field:

> *"I'm in such a better place than I was four years ago. You know, depression and everything… it's helped me...it picks up your mood that you're actually doing something for other people… doing the* [DWELL] *Ambassador programme has given me a sense of purpose...it's been life changing"* [DWELL Ambassador, UK 1]

> *"Since I became a* [DWELL] *Ambassador, I have been more serene, I have smiled more...I make them laugh, which I did not do before. I was a reserved person, I was always at home. I blossomed."* [DWELL Ambassador, France]

6.4 Sustainability of the DWELL Programme

Longitudinal qualitative interviews were conducted with a sub-sample of 16 DWELL participants who had completed the programme more than 24 months ago (up to 48 months). The 'legacy' interviews were conducted between January and May 2022, with the purpose of exploring sustainability of the programme with those who completed the programme before March 2020.

Table 5. Legacy interview demographics

	UK1	UK2	NL	Total
No. of interviews	8	5	3	16
Gender				
Male	6 (75%)	4 (80%)	1 (33%)	11 (69%)
Female	2 (25%)	1 (20%)	2 (67%)	5 (31%)
Year of DWELL completion				
2018	2 (25%)	1 (20%)	0	3
2019	3 (37.5%)	3 (60%)	3 (100%)	9
2020	3 (37.5%)	1 (20%)	0	4

6.4.1 Legacy of the DWELL programme

"Life gets in the way"

Participants who had completed the programme more than 24 months ago reported that "life gets in the way" at times when it comes to managing long-term conditions such as diabetes. Individual and circumstantial events that had impacted on the progress of participants included medication changes, weight loss or gain, family issues, bereavements, and the occurrence of other illnesses (including COVID-19).

'I have broken that wall down'

There a varied spectrum of experiences, from those struggling to manage their diabetes to those able to sustain most or all changes they had achieved after taking part in the DWELL programme. Most common issues were in relation to eating behaviours and physical activity.

In terms of eating behaviours, many participants had sustained lowering their carbohydrate and sugar intake, were managing their portion control, eating less processed food, experimenting with intermittent fasting, calorie counting, and reading and understanding food labels.

In relation to physical activity, participants spoke of continuing changes they made through DWELL, including more walking, gardening, swimming, and chair-based exercises.

There was also evidence that learning obtained during wellbeing sessions had remained with participants long after the end of the programme:

> *"I remember one session,* [the facilitator] *gave us a lump of plasticine … I built a wall out of bricks. And on the other side of the wall were all the things that I need to sort out which, when I was working, I never had the time to do. I'm very poor at throwing things away. So that's one of the tasks. I have broken that wall down, and I'm pouring through the wall. I am getting rid of huge amounts of paperwork that have accumulated over 20 plus years"* [UK1, 2019 cohort]

"Progress is not a linear journey"

There was a strong sense of progress with participants feeling they were heading in right direction since DWELL, but there was also recognition that the journey was not linear. The trend observed with DWELL long-term quantitative outcomes (see Report 3: Participant Outcomes), where physiological measures seem to have improved, dropped then improved again, was reflected in the interview data:

> *"There are times when it goes completely out of control. And then I sort of pull it back in…I know what I need to do, it's just a matter of doing it."* [UK1, 2020 cohort]

Empowerment and Autonomy

Participants continued to feel empowered to raise issues about their diabetes care with their physician/GP and other healthcare professionals since DWELL. There was a sense of autonomy that developed from increased knowledge, confidence, and acknowledgement that management of the condition was a two-way process:

> *"I kept saying hang on a minute, the nurses and everything…in some ways, they didn't know what they were doing. They were just saying take this and take that. And I turned around and*

said 'Well. I'm not going to…I'm not going to not take so much Metformin,' so I only have one in the morning and one in the afternoon, and we will review that" [UK1, 2019 cohort]

6.4.2 Impact of COVID-19 pandemic

All 'legacy' participants were adversely impacted in some way by the pandemic. As highlighted by participant feedback at the end of the programme, there was a sense of everyone being "in the same boat", whereas the pandemic brough to the fore health inequalities, as reported in a UK Public Health report 'Disparities in the risk and outcomes of COVID-19' (PHE, 2020).

Many participants were less physically active during lockdown restrictions. Half of them had experienced poor wellbeing, including depression, sleep difficulties, employment challenges and isolation. There was increased anxiety about catching COVID-19, and uncertainty whether having type 2 diabetes meant they were clinically vulnerable and at higher risk of complications:

"I was terrified to be around people, even my mum - if she'd been near the grandchildren, I wouldn't see her. I probably saw her four times the first year. And even after she'd gone, and she's as clean as me and everything, I'd go around with my steamer and just steam everything, because I was just that paranoid about it." [UK1, 2018 participant]

Conversely, there were some positive impacts of the COVID-19 pandemic mentioned by participants such as improved eating habits – restrained eating and better food choices. Participants reflected on the lockdown period as an opportunity to focus on their health and wellbeing, having more time to explore hobbies at home, being more physically active – e.g. walking and gardening.

6.4.3 Recommendations for programme delivery in the future

Participant recommendations about future iterations of the programme were mainly based around increased follow-up support and consideration of delivery options.

Follow-up support

Similar to feedback received at the end of the programme, 'legacy' participants suggested that continued contact and support after the programme would be valuable, particularly in a group format, possibly on a weekly or monthly basis:

"One of the biggest things for me was the usefulness of being with other people because diabetes, or indeed any illness, can be a very isolating thing, and it's great to be in a room with lots of other people that are in the kind of similar position … And you know, just the camaraderie, if you will, was I thought perhaps the most important thing that helped." [UK2, 2019 cohort]

Suggestions for the content of follow-up sessions or groups included refreshers on the education element, updates on diabetes guidelines, weigh-ins and HbA1c checks. Those who attended the programme with their partners found this opportunity very valuable, and suggested that partners should be involved in follow-up sessions. There were also suggestions about involving DWELL Ambassadors in ongoing support activities.

Online or blended delivery

'Legacy' participants spoke about the potential for online or 'blended' (in-person and online) sessions, particularly given that people became more familiar with communicating via technology since the COVID-19 pandemic. Although in-person sessions helped to aid group interaction and cohesion, and were indeed necessary for cooking sessions, it was felt that some sessions could be delivered virtually, or at least for online attendance to be offered as an option. This was particularly the case for the UK1 site, where participants attended two sessions per week on consecutive days.

Key points from DWELL Outcomes

- Qualitative feedback illustrated significant positive outcomes of the DWELL programme:
    - Enhanced self-management of diabetes
    - Making important lifestyle changes
    - Enhanced wellbeing (for programme participants and DWELL ambassadors)
- Sustainable outcomes were elicited from 'legacy' participants:
    - Recognition that progress is not a linear journey
    - Sustained empowerment and autonomy
    - Navigating challenges during the COVID-19 pandemic
- Participant recommendations for programme delivery in the future include:
    - Provision of follow-up support
    - Considering online or blended delivery of the programme



7.Conclusion

The DWELL Logic Model set out the anticipated delivery intervention components, mechanisms and intended outcomes of the programme. This report illustrates how the programme unfolded in reality compared to the original plan.

Each site delivered the 12-week DWELL programme within their individual national and organisational context – different venues, environments, capacities, and resources.

Although all sites delivered the same programme content over 12 weeks, the course structure varied, and each of the four elements of the programme – education, nutrition, physical activity and wellbeing – were implemented in different ways, depending on available resources at each site.

The individualised delivery style, tailored to individuals, groups and environment, was a major facilitating factor in achieving positive change in the DWELL programme. Operational challenges, especially at the start of the programme, included demand on available resources, difficulties in participant recruitment at the time when the programme was not known to the healthcare professionals, and barriers to implementing particular activities, in particular physical activity, due to lack of access to available facilities and expertise. Most of these challenges were overcome during the implementation period.

Three main mechanisms utilised in the DWELL programme were peer support, motivational interviewing and goal setting. Peer support was experienced among participants and was also referenced by DWELL facilitators and Ambassadors. Previous research highlights the importance of social networks and social participation acting as protective factors to and determinants of health (Dahlgren and Whitehead, 1991; Marmot and Bell, 2012). Motivational interviewing proved to be a highly effective mechanism that enabled participants to be proactive and take control of their lives, including the management of diabetes. Autonomous motivation relates to doing things for intrinsic reasons, which is predictive of successful self-care.

Among positive outcomes reported by programme participants, DWELL staff and Ambassadors, included significant lifestyle and behaviour changes due to enhanced knowledge and illness beliefs, and wellbeing outcomes such as enhanced empowerment, self-care, social wellbeing and quality of life.

8. Recommendations

Recommendations for further implementation of the DWELL or similar psychoeducation programmes for other long-term conditions are set out below:

- Ensure adequate funding and budget for necessary resources, including staff time, evaluation and appropriate venues
- Have buy-in from local GPs, healthcare professionals, local services providers and community organisations to assist with promotion, referral and recruitment processes
- Facilitate programme cohorts at different times of the day (i.e. morning, afternoon, evening sessions) and virtual/online options to ensure there is equal provision for all
- Consider relevance of programme to people who are ‘pre-diabetic’ or on the borderline, i.e. as a preventative intervention
- Maintain and strengthen involvement of DWELL Ambassadors to help deliver the programme, potentially as a formal/paid role
- Establish a robust training and development curriculum for DWELL staff and Ambassadors
- Develop provision for post-programme follow-up, in line with the National Institute for Clinical Excellence quality standards in the UK to provide annual refreshers of education programmes (NICE, 2015), such as regular drop-in sessions for all previous participants to reaffirm learning, obtain advice and maintain social networks, as well as keeping in touch with participants via newsletters and updates.

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Appendix 1 – DWELL Participant Goals: thematic analysis

THEME	SUB-THEME	CODES
MANAGEMENT OF ILLNESS	CLINICAL ASPECTS	Prevent progression/future complications & avoid infection
		Reversal of T2DM
		Decrease pain/pain management
		Maintain health
		Reduce risk of falls/improve balance
		General/overall health benefits/lifestyle changes
		Sexual health
		Sleep related
		Reduce fatigue/Increase energy
	METABOLIC HEALTH	Lower/manage blood glucose (HbA1c)
		Weight related - weight loss/maintain weight
	DIABETES EDUCATION	Obtain information/knowledge about T2DM
		Maintain habits/lessons learnt about diabetes
	MEDICATION MANAGEMENT	Medication (treatment) - not have to start taking it
		Medication (treatment) - stop/reduce
	SUPPORT FOR SELF MANAGEMENT	Acceptance of diagnosis
		Better management of condition
		Take condition more seriously
		Find support
		Finish DWELL course
MANAGEMENT OF NUTRITION	EATING BEHAVIOURS	Reduce snacking
		Reduce alcohol intake
		Reduce carbohydrate intake
		Reduce sugar intake
		Change eating habits (Praxis) - Plan/make better choices and/or change habits/eat less
		Maintain diet
		Less guilt around eating
		Understand emotional eating/habits
	NUTRITION EDUCATION	Learn new recipes/skills
		Better understanding of nutrition and food (learning) - Understand diet impact of different food/drink/nutrition on T2DM
		Address/reduce cholesterol
MANAGEMENT OF PHYSICAL ACTIVITY	PHYSICAL ACTIVITY & MOBILITY	Chair-based exercises
		Dog walking & More walking
		Enhanced general fitness/mobility/exercise/increase exercise
		Go to the gym
		Swimming
		Maintain exercise
		Resume exercise
	PHYSICAL ACTIVITY EDUCATION	Learn more about exercise and impact on diabetes
		Learn about the human body

MANAGEMENT OF WELLBEING	EMPOWERMENT & MENTAL WELLBEING	Address mental/emotional challenges (including: guilt, hoarding, anxiety, depression)
		Mental balance
		Enhance or maintain positivity/enjoyment of life/wellbeing/quality of life/fun
		Feel in control/empowered/independence
		Mindfulness/meditation/relaxation/reduce stress
		More confidence
		Maintain wellbeing
	QUALITY OF LIFE	Purpose/meaningful activities & Take up new/rediscover/maintain old activities/hobbies
		Self-care
		Socialise & reduce social isolation/form friendships (enhance social wellbeing)
		Increase/maintain motivation
		Evaluate mental health
		Positive impact on family
		Travel
		Finance goals
		Job/work related
		Stop smoking
		Become patient ambassador & Help/support/work with others with T2DM
		Participate in a research project




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