

## iDEAL Group Position Statement

# How to maximise the impact of diabetes consultations: The perspective of people living with diabetes

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The iDEAL (**Insights for Diabetes Excellence, Access and Learning**) Group exists to enable the delivery of best practice in diabetes care for every person living with diabetes. We are a highly engaged independent multidisciplinary team of representative experts with a visionary outlook to improve diabetes care outcomes across the UK.

The group includes the perspective of people living with diabetes, clinical service provider organisations and their professional bodies as well as the main charities and interest groups. This enables networking and outreach to gather, evaluate and share evidence to reach practitioners delivering diabetes care and those in need of it.

Our programme of action is focused on harnessing our professional expertise to build consensus, network, research, share knowledge and collectively seek to make things better; both for practitioners working in partnership with and for people living with diabetes.

### KEY RECOMMENDATIONS

- Each person with diabetes (PwD) is the expert in their life and their experience of living with diabetes.
- Every PwD should be given access to diabetes self-management education and behaviour change support including individual, group and digital offerings depending on their preferences.
- Every consultation is an opportunity to share knowledge and understanding between the PwD and Health Care Professional (HCP), working in partnership to explore the person's informational and support needs and the HCP gaining an increased depth of understanding of the individual.
- Remote support and access in out of office hours, increases accessibility, especially when digital options such as WhatsApp, Skype, Attend Anywhere, text messaging, email and remote chat and consultation features of digital systems are used effectively.
- The language tailored with cultural awareness and competence employed in the consultation needs to be personalised to the individuals' requirements, health and digital literacy and learning style and reflect Language Matters (2018).
- Emotional wellbeing and psychological concerns can hinder individual self-management added and the importance of emotional health needs to be acknowledged and explored in each consultation by each HCP.
- PwD can experience judgement and stigmatization from some HCP encounters. This can be discriminatory and needs recognition and challenging to reduce and avoid these experiences for PwD.
- The use of the acronym '**LET'S TALK NOW**' can help guide partnership approaches in consultation conversations and can promote balance and inclusivity of choice in Diabetes Care.

## INTRODUCTION

PwD are diagnosed with and live with a complex, demanding and relentless condition (Doherty et al, 2012, Lhussier et al, 2013). It is imperative that any and every contact, whatever the situation or occasion is used to maximum effect for the benefit of the individual and their circumstances. Thus creating a safe space in consultations whereby every PwD can explore without fear of judgement their everyday struggles, their concerns and any gaps in their understanding. Providing them with the scaffolding to continue to engage in their diabetes self-care and seek support at times when they may be struggling.

PwD engage with HCPs, across a wide variety of settings across the healthcare arena. Consultations occur in primary care, in the individuals own home, in specialist outpatients or at the bedside. These interactions involve interdisciplinary conversations with the coming together of experts in terms of the PwD and HCPs, acknowledging respect and partnership. Anecdotal evidence suggests on many occasions, the experiences of PwD is a positive one, where mutual trust and benefit has been experienced. However, conversely many PwD have reported experiencing stigma, judgement, labelling, fear, disablement and discrimination in some consultations by some HCPs. This can be due to lack of knowledge or training of the HCP, inexperience, misunderstanding of the HCP as regards their role in the consultation, attitude, or indeed stress, unawareness or even burnout of the HCP also (Egan et al, 2018).

This position paper echoes the role of HCPs and their education (Phillips et al, 2019) and the support they require in developing and maintaining their consultation approaches (Odiase et al, 2021). Cascading skills to peers can enable the building and scaffolding of best practice in diabetes care.

A positive experience of healthcare encounters engender PwD to have valued experiences and to feel involved, respected and heard.

However, HCPs need self-awareness to try to minimise or eradicate the negative experiences for PwD, as the lasting impact of a negative encounter can be traumatic for the individual, creating an ongoing distrust in relationships between PwD and HCPs, which can have far reaching emotional and psychological effects, beyond the few words exchanged. The language used, the words shared and the context they are shared within also can have a lasting effect on the PwD (Language Matters, NHS England, 2018).

## WHY DOES THIS MATTER FOR THE PWD?

- **Acknowledging the individual**

**All aspects of diabetes care need to acknowledge that it is the PwD that lives with and manages their condition.**

PwD require HCPs who support, listen and enable solution-focused approaches for each individual in their learning and gaining of new skills (Odiase et al, 2021). Rather than making statements or judgements for PwD without including them in the decision-making or planning process, this can be negative and somewhat paternalistic (Diabetes UK, 2014). Diabetes care does require the inclusion of the people it is intended to serve in terms of design, timings and access and not the convenience of the HCPs providing the same. Respecting each individual's choice regarding their healthcare encounters avoids some of the rigid 'due to policy' recall systems in place experienced by some PwD and their access to aspects of their diabetes care. Additionally, recent fears about services being closed due to Covid-19 have created unprecedented delays in some people feeling able to seek care in a timely manner (Carr et al, 2020).

- **How do PwD know what they need to know or what questions to ask?**

This comes through effective engagement with each person as an individual, but also inclusion and referral to the most appropriate structured educational opportunity, for the individual to engage and learn the skills to live with their diabetes. This also requires the PwD to have access to knowledgeable HCPs who know how to signpost people and recognise that 'one size' never fits everyone's individual needs. Diabetes care does require the inclusion of the people it is intended to serve and not the convenience of the HCPs, for example in terms of access and timings of virtual appointments and return to face to face clinics. Factors that widen health inequalities need to be dealt with to reach out into Increasing use of digital and remote consultation is encouraged to support PwD to manage their diabetes alongside their busy life commitments, as each is mutually inclusive to the other. Consultation approaches and diabetes etiquette for people who don't have diabetes have been recommended by The Behavioural Diabetes Institute (2009) - this offers HCPs useful insight into their approaches in healthcare encounters with PwD.

- **Building a partnership**

The rights of every PwD needs to be clearly articulated from diagnosis and at each consultation conversation or contact wherever this may occur across the NHS, so every individual knows what they should expect.

Diabetes UKs (2019a) 15 healthcare essentials reinforces this approach and encourages each PwD to have an active role and voice in their care. NHS Audit Report (2019) did highlight inconsistencies in the delivery of the 15 healthcare essentials across England and Wales. This has been further exacerbated during the recent lockdown, so a re-focus on diabetes care is timely to help support and encourage people to access services and have their voice heard in consultation conversations also.

Mutual compassion between the PwD and HCP can help create a partnership approach with the recognition that compassion is necessary for each in the consultation process to avoid misunderstandings, misperceptions, disconnect or hostility (Egan et al, 2018).

Krejany and Jiwa (2019) suggested that using person-centred, directed goal setting on the journey with each PwD can help people engage and understand their agreed therapeutic targets in their diabetes care journey. Krejany and Jiwa (2019) further suggested that in order to improve diabetes care the focus falls on educational interventions, whereby perhaps HCPs need to learn to 'say it better' and for PwD to be encouraged on 'how to hear the messages'. However, the individual's voice can be lost in this approach and HCPs need to be mindful of each PwDs' lived experiences, capacity, choice and readiness to make changes if required and acknowledge and respect these challenges. The person-centred, individualised approach needs to hear and listen to each PwD, to respect their situation, their beliefs, experiences, fears and acknowledge their journey and autonomy. This is where iDEAL recommend using the '**LET'S TALK NOW**' added approach.

- **Supporting choice**

Every PwD should be informed of who and how they can approach for help. This needs re-igniting post rigid virtual clinic approaches with primary care often not offering timed virtual appointments relying on ring back only facilities (Gilbert et al, 2020). With home working for many people, this has caused potential barriers in diabetes care engagement.

Additionally, there should be flexibility in the choice of the individual which HCP they wish to see, and not dictated by the diabetes service needs, but by the PwDs' own needs. This also resonates the requirement for every HCP to also explain how their diabetes service works. So every PwD can gain the most from the service and not be blamed for any misunderstandings if the structure or service differs in approach from any they had previously experienced. This includes written communications and appointment letters, so each PwD knows how virtual services, consultations and clinics run and what is expected of them. This further reflects the timing and situation of virtual consultation or clinic recall and suggests some discernment for individual needs and choice also.

Respecting choice is also important so if the PwD declines, for example, to be weighed this is respected and not labelled as 'non-compliant' or refusal, as they will always be a salient reason for this request. Furthermore, HCPs need to consider the impact of their clinic situation in terms of asking people to have their blood pressure taken while sitting on weighing scales is not ideal in terms of person centred engagement or BP management. Simple ergonomics and including PwD in clinic setups offers valuable insight into the impact of these situations where HCPs might overlook this.

- **Tailoring the consultation**

It has been recognised that consultation is an art and very much has its impact affected by multiple co-factors such as delivery style, communication skills, personality type, and HCP-PwD connectivity (Odiase et al, 2021). 'PwD versus HCP' centredness and the degree to which the consultation or healthcare encounter occurs can influence the experience of both the individual and the HCP (CPPE, 2014, Denness, 2013, Bailey, 2014).

Different styles of consultations affect outcomes and the emotional response of the PwD. Many PwD have reported negativity and/or fear about their planned diabetes review for fear of judgement from the HCP. Additionally, some PwD can experience diabetes-related distress and self-imposed feelings of shame from their diagnosis, which can hinder them from accessing help.

Dickinson (2017) recognised that PwD are exposed to the language HCPs use both in speaking and writing and those words may contribute to an already stressful illness experience.

The global recognition of the language used in diabetes care and management in recent years (Dickinson et al, 2017, Speight et al, 2012, Kyle et al, 2014) has advocated HCPs to adopt and evolve their language in the clinical setting (Language Matters, NHS England, 2018).

- **Language matters**

For many years, HCPs working in care, have acknowledged the inappropriateness of words such as “compliance” and “adherence” in diabetes care (Speight et al, 2012, Anderson & Funnell, 2000, Funnell & Anderson, 2000), yet these labelling words are still used by many HCPs (Dickinson, 2017). Whilst HCPs are encouraged to embrace an encouragement model for delivering education and care, however, frequently the language being used in diabetes care and education is not always consistent with that approach (Dickinson, 2017).

The type of consultation and the HCP who interacts at that time with the PwD is influential, as the context and content will differ according to the individual situation, so different approaches are needed. However, the inexperience or disconnect of the influence of words or meaning experienced by PwD can be detrimental. If the HCP does not recognise or realise the influence their individual interaction has on the individuals’ experience, this can create barriers and distance, and engenders disengagement and mistrust with diabetes services, due to fears of judgement or blaming.

As PwD experience care across the wide arena of the NHS and social care providers, it is essential to share best practice and education for each HCP to adopt and encompass best consultation approaches, that their language really does matter and that PwD are the experts in their lives and experiences.

- **Partnership approaches**

As Odiase et al (2021) also recognised that the fear that some PwD recount from the first conversations at diagnosis can cause potential diabetes related distress and difficulty in both accepting and engaging with their diabetes (DeGroot et al, 2019). This must be acknowledged by HCPs in their everyday encounters with PwD, and the situation the consultation conversation occurs in.

HCPs need to recognise the PwD might not be able at the point of the consultation, to absorb their diagnosis or diagnosis of a consequence of living with diabetes. This requires time to assimilate these new circumstances into their lives, often alongside a multitude of competing health needs or social, economic, family or emotional demands within their lives also (RCGP, 2018, Stafford et al for The Health Foundation, 2018). This requires HCPs to approach individual needs with understanding and using different approaches, appropriate terminology, language skills and emotional intelligence depending on the PwD’s situation, emotional wellbeing and coping skills at that point in their diabetes journey (Language Matters, 2018).

The trauma that diagnosis can engender can last and many PwD can recall the language used and the lasting effects this had, especially in the way discussion about potentially preventable complications are framed. HCPs have a role at diagnosis as does each PwD and their families in being enabled to hear and assimilate their altered situation. Increases in diagnosis occurring during Covid-19 in type 1 diabetes (Ng et al, 2021), reinforce HCPs need for improved awareness of the psychological fear and response to a new diagnosis of type 1 or type 2 associated with extreme illness. Adaptation and developing coping abilities will take adjustment and time to physiologically recover from such an acute diagnosis (Petrie et al, 2020, Pouwer et al, 2020). This can cause individuals affected to find long-term self-management more troubling, compared to a less dramatic diagnosis when an individual is less acutely unwell (Stewart, 2020). Adjustment does take time post diagnosis so framing consultations in knowing the individual and their story is always profoundly helpful in making their consultation conversations and adaptation to their diagnosis more meaningful (Shersher et al, 2021, Phillips, 2021).

- **Tacking health inequalities and promoting individualised care**

The cultural context of the individual and their circumstances needs acknowledgement by all HCPs and the spiritual beliefs and ancestry of each PwD will influence their understanding and acceptance or rejection of their treatment choices. This also is where education for HCPs in cultural awareness is apposite as detailed by iDEAL in their position statement about access to CPD for every HCP (Phillips et al, 2019). Also, the socioeconomic status of the PwD is vital as if suggestions about accessing services are inaccessible in terms of economics, then alternative suggestions need to be included, to prevent embarrassment, guilt or disengagement. Reaching out to socially vulnerable and hardly reached

communities facilitates HCPs listening to their local communities, addressing health inequalities and tailoring diabetes services accordingly (Phillips, 2021). With the growing utilisation of telehealth approaches for diabetes care delivery, it is so much so important that such innovative approaches do not widen the health inequality gap and further disadvantage the already hardly reached communities (Wallace et al, 2020). The PwD should be offered the most appropriate telehealth medium for their review, which allows for optimal engagement and connectivity between PwD and HCP.

## PSYCHOLOGICAL WELL BEING

PwD have reported that it is important for HCPs to understand and fully appreciate the relentlessness of diabetes and the often overwhelming burden diabetes places on an individual 'on top of life' already. Often PwD suggest that HCPs can demonstrate a lack of knowledge, empathy or compassion regarding the lived experience of diabetes as a challenging condition to manage and integrate into their life. The lack of shared educational experiences and networking opportunities for joint engagement can create a disconnect between PwD and HCPs, where each has many valuable experiences, suggestions and similarities to offer the other.

Hendrieckx et al, (2019) questioned if there is a lack of emphasis on ensuring emotional wellbeing and impact of living with diabetes are explored. PwD have requested honesty in the consultation from their HCP and that this can be encouraged in a collaborative mutually nurturing way to support disclosure and avoid judgement. Additionally, PwD have suggested they value HCPs admitting they want to help but may not know how to help or may not understand the extent of the diabetes related or life related issues being faced by PwD.

As HCP understanding and experience of diabetes care evolves, it is fundamental to realise the strong relationship between diabetes and emotional wellbeing, which can yield diabetes fatigue, distress, burnout, depression (Holt et al, 2014) and/or ambivalence.

PwD value recognition of the emotional burden that diabetes can cause, and that often diabetes and emotional health are interrelated (Stewart, 2020).

This also supports the need for collaborative approaches and avoidance of blame, judgement or different approaches experienced from anecdotal evidence from PwD.

- **Signposting**

PwD welcome signposting so they know how and where to get help as required in between review appointments. Whether this is by email, face to face, Skype or text messaging, each offers opportunities for engagement and solution finding (Cafazzo, 2019, Shan et al, 2019). HCPs can be the gatekeepers for needs outside of diabetes care that really matters to individuals and their families (Duncan 2019, Phillips, 2021). PwD also have the right to request a referral to other diabetes services and this should be supported also (Diabetes UK, 2019).

## CONSULTATION AND COMMUNICATION SKILLS

iDEAL suggests that PwD need to be encouraged to take a more active role within their consultations creating a safe space where people can really say what they think and need, in a supported environment, where blame and judgement have no place. Many PwD report feeling uncomfortable in front of HCPs who they may perceive to 'know best'. Yet the PwD truly knows the realities of living with diabetes and only they can really judge and assimilate the effect of this on their lives and that of their families. This requires HCPs to have a willingness to put them at the centre of their care and time to listen to the PwD.

PwD value being supported for inclusion in their consultations so their voice is heard and their views and opinions can be respected.

Smooth communication between services in diabetes care is also fundamental, especially between primary and secondary care, with PwD receiving copies of letters agreed with them and by them before being sent.

This is an exemplar of best practice as advocated by The Academy of Medical Royal Colleges, (2018). This aims to reduce duplication and maintain engagement with continuity of care and advice shared and agreed. PwD who have agreed the letter together in clinic as it is dictated have expressed how helpful this has been and how they felt respected and engaged

in their care. However PwD who received letters sent post clinic who have not agreed the contents or disagreed with the context of the letter have commented how disempowering this has felt and how it lacked partnership working with them as individuals. This is where HCPs need to reflect on the experiences of PwD and consider reviewing their clinic system to reduce unnecessary professional barriers being in place.

## ENSURING FIDELITY OF THE PROCESS

Winkley et al, (2019) suggests that evidence from the past 25 years has demonstrated the association between medication beliefs and medication-taking behaviour with people with Type 2 diabetes. This is a vital area for HCPs to address medication worries or concerns fully and not assume that the individual fully understands or recognises the need for medication intensification, especially if they are feeling well. Judgemental reactions to not taking prescribed medications have no place in diabetes care, where Winkley et al's (2019) research suggests that a more appropriate way is for HCPs to demonstrate the utility of diabetes medication with each individual within the consultation. This allows PwD to express their choice for that medication and for HCPs to use open questions seeks to gain feedback and avoid assumptions. Phillips, (2021) also identified clinical inertia and habit in prescribing can cause barriers for some communities in accessing care. Reaching out into local or harder to reach communities is paramount to reduce inequalities.

PwD can fear the power imbalance of consultations and feel that the HCP knows best, so can miss opportunities to gain clarification or question decision-making. Winkley et al (2019) highlight this is where misunderstandings and miscommunication have occurred, especially if individuals are spoken 'at' rather than spoken 'with'. This echoes the essence of why person centred approaches using language that matters in a vital element of partnership working with every PwD.

## CONCLUSION

The feedback from a variety of PwD has offered a rich insight into this position paper and offers perspectives that HCPs may not have considered in their everyday working alongside PwD.

As diabetes care is about the life of the individual living with diabetes, not about the diabetes in the life of the individual.

Therefore iDEAL suggests a useful way to establish and enable productive and valued consultations and healthcare encounters is to enable a pathway of care the individual understands, is part of and is person-centred so PwD can engage with this without fear of judgment and really focus their consultation to their needs. iDEAL advocates adoption and use of this approach **'LET'S TALK NOW'**.

## 'LET'S TALK NOW'

L

Let the Person with Diabetes (PwD) have their choices heard in shared decision making

E

Encourage the PwD to share their emotional concerns without feeling judged

T

'Two ears One mouth' proves listening twice as much as speaking is the path to shared decision making

S

Seek to meet the PwD where they are in their life rather than where you would like them to be

T

Talk with the PwD not at the PwD

A

Assess and accept what the PwD feels is within his/her control, and their right to disengage

L

'Language matters' and turns the conversation into a safe haven for PwD to share their feelings

K

Keep to key messages and practical points so PwD can make informed shared decisions

N

Not managing but walking alongside PwD

O

Outcomes should be individualised and person focussed

W

Working in partnership enhances PwD self-efficacy

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**K** Keep to key messages and practical points so PwD can make informed shared decisions

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**O** Outcomes should be individualised and person focussed

**W** Working in partnership enhances PwD self-efficacy



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