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. We lobby policymakers and challenge perceptions to encourage the redirection of resources and influence education and training opportunities to meet the needs of all individuals living with diabetes.

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 living with diabetes (PLwD) is the expert in their life and their experience of living with diabetes.
- Every PLwD 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 with the PLwD 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 to out of office hours, increases accessibility, especially using digital options such as WhatsApp, Skype, text messaging, email and remote chat features of digital systems.
- The language tailored with cultural awareness and competence employed in the consultation needs to be personalised to the individuals requirements, health literacy and learning style and reflect Language Matters (2018).
- Emotional wellbeing and psychological concerns can hinder individual self management and the importance of emotional health needs to be acknowledged and explored in each consultation by each HCP.
- PLwD 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 PLwD.
- Encourage the use of Diabetes Etiquette approaches recommended by The Behavioural Diabetes Institute (2009).

This position paper acknowledges that the optimum outcome is for PLwD to achieve better outcomes, as defined by each individual. This echoes and mirrors the accompanying position paper by iDEAL (Odiase et al, 2020) about the role of HCPs in consultations with PLwD. This position paper offers perspectives from the experiences of many PLwD who have been consulted about this position paper. Their experiences offer HCPs rich insight into what they have experienced and wished the HCP had acknowledged during their consultations with some HCPs.

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INTRODUCTION

PLwD 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 PLwD 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.

PLwD 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 PLwD and HCPs, acknowledging respect and partnership. Anecdotal evidence suggests on many occasions, the experiences of PLwD is a positive one, where mutual trust and benefit has been experienced. However, conversely many PLwD have reported experiencing stigma, judgement, labelling, 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, 2020). Cascading skills to peers can enable the building and scaffolding of best practice in diabetes care.

A positive experience of healthcare encounters engender PLwD 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 PLwD, as the lasting impact of a negative encounter can be traumatic for the individual, creating an ongoing distrust in relationships between PLwD and HCPs, which can have far reaching emotional and psychological effects, beyond the few words exchanged.

WHY DOES THIS MATTER FOR THE PLwD?

- Acknowledging the individual

  All aspects of diabetes care need to acknowledge that it is the PLwD that manages their condition.

  PLwD require HCPs who support, listen and enable solution-focused approaches for each individual in their learning and gaining of new skills (Odiase et al, 2020). Rather than making statements or judgements for PLwD 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 individuals choice regarding their healthcare encounters avoids some of the current rigid ‘due to policy’ recall systems in place experienced by some PLwD and their access to aspects of their diabetes care.

  This also echoes the position paper about the importance of access to recent iDEAL HCP Education in Diabetes Care (Phillips et al, 2019), is essential to this process.

- How do PLwD 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 PLwD 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 providing the same, for example in terms of access and timings of face
to face clinics. Increasing use of digital access is encouraged to support PLwD 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 PLwD.

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

Diabetes UKs 15 healthcare essentials reinforces this approach and encourages each PLwD to have an active role and voice in their care.

However, the NHS Diabetes Audit Report (2019) highlight inconsistencies in the delivery of the 15 healthcare essentials across England and Wales.

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

Krejany and Jiwa (2019) suggest that using person-centred, directed goal setting on the journey with each PLwD can help people engage and understand their agreed therapeutic targets in their diabetes care journey. Krejany and Jiwa (2019) further suggest 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 PLwD to be encouraged on ‘how to hear the messages’. However, the individuals voice can be lost in this approach and HCPs need to be mindful of each PLwDs 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 PLwD, to respect their situation, experience, fears and acknowledge their journey and autonomy.

• Supporting choice
Within diabetes care, it is important to use the #HelloMyNameIs Campaign advocated by Dr Kate Granger.

So every PLwD knows who they can approach for help and also who their named nurse, dietitian, podiatrist, psychologist, pharmacist or doctor is.

This is fundamental for a person-facing compassionate care approach, but still is not being experienced consistently across all diabetes services in acute or primary care.

Additionally, it should be the choice of the individual which HCP they wish to see, and not dictated by the diabetes service needs, but by the PLwD’s own needs. This also resonates the requirement for every HCP to also explain how their diabetes service works. So every PLwD attending can gain the most from the service and not to be blamed for any misunderstandings if the structure or service differs in approach from any they had previously experienced. This includes in written communications and appointment letters, so each PLwD knows how clinics run and what is expected of them. This is where consulting regarding service provision with PLwD is a fundamental requirement to be person facing (Diabetes UK, 2014). This further reflects the timing and situation of clinic recall and suggests some discernment for individual needs and choice also.

Respecting choice is also important so if the PLwD 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 PLwD 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-PLwD connectivity (Odiase et al, 2020). ‘PLwD 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 PLwD.

Many PLwD have reported negativity and/or fear about their planned diabetes review for fear of judgement from the HCP. Dickinson (2018) recognised that PLwD 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 UK clinical setting (Language Matters, 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 frequently (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 spoken and written words HCPs use contribute to the context in which people live with and manage their diabetes. Through context, people create meaning (Marrero et al, 2013, Fleishman, 1999); therefore, negative words can lead to negative meaning.

The type of consultation and the HCP who interacts at that time with the PLwD 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 PLwD 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.

The HCP consultation approach should be consistent, experienced and offer individualised education to support recognition and discernment in the conversation with each and every PLwD, to meet their needs and not the service needs in terms of template ticking - this is a fundamental need.

As PLwD 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 PLwD are the experts in their lives and experiences.

• Partnership approaches

As Odiase et al (2020) also recognise that the fear that some PLwD 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 PLwD, and the situation the consultation occurs in. HCPs need to recognise the PLwD 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 PLwD’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 PLwD 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 PLwD and their families in being enabled to hear and assimilate their altered situation.

Sub-optimal or poor consultations are a complication of diabetes care, not the PLwD and this is where every HCP needs to recognise the effect their words and phrases can have on each individual and their family.

• Individualised care
The cultural context of the individual and their circumstances needs acknowledgement by all HCPs and the spiritual beliefs and ancestry of each PLwD 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 PLwD 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 communities facilitates HCPs listening to their local communities and tailoring diabetes services accordingly.

PSYCHOLOGICAL WELL BEING

PLwD 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 PLwD suggest that HCPs can demonstrate a lack of knowledge 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 PLwD and HCPs, where each has many valuable experiences, suggestions and similarities to offer the other.

Thomson and Khan (2015) questioned if there is a lack of emphasis on ensuring emotional wellbeing and impact of living with diabetes are explored. PLwD 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, PLwD 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 PLwD.

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.

PLwD value recognition of the emotional burden that diabetes can cause, and that often diabetes and emotional health are interrelated.

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

• Signposting
PLwD 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, other than the traditional six monthly review appointments (Cafazzo, 2019, Shan et al, 2019). If the PLwD who needs help does not know or cannot access their named HCP in between regular clinic appointments. HCPs can be the gatekeepers for needs outside of diabetes care that really matters to individuals and their families (Duncan 2019). PLwD 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

As Odiase et al (2020) for iDEAL noted some studies (Rogers, 1957; Powell et al, 2016, American Diabetes Association, (2016), NHS Right Care: Diabetes Pathway, 2018) highlighted the benefit of an individualised person-centred approach as a therapeutic relationship that would self-empower the individual to work towards self-caring solutions. iDEAL suggests that PLwD 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 PLwD report feeling uncomfortable in front of HCPs who they may perceive to ‘know best’. Yet the PLwD 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 PLwD.

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

Life is very busy and many PLwD ‘just get on with it’ and do not separate their diabetes out in order to set individual goals and targets. Increasing use of glucose technology is helping this, and examples of great tools available to prepare for consultations are available such as the Health Innovation Network with Kings Health Partners Type 1 Consultation Tool (2017). A similar approach from diagnosis would be really useful for use in primary care for PLwD also, alongside the consistent use of Diabetes UK (2019) Information Prescriptions for and by HCPs and PLwD.

Smooth communication between services in diabetes care is also fundamental, especially between primary and secondary care, with PLwD 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. PLwD 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 PLwD 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 PLwD and consider reviewing their clinic system to reduce unnecessary professional barriers being in place.

DISCUSSING RISK AND COMPLICATIONS

When talking about the potential risk of complications, iDEAL expert panel members and feedback from the experiences of PLwD consulted both suggest that the best way to approach risk is by an open, honest, non-judgemental and individualised conversation. PLwD fear complications, fear judgement, fear blame and can experience shame for situations, often out of their control, and never their choice. As recognised by the International Diabetes Federation (IDF, 2019) and advocated by PLwD advocates (Grumpy Pumper & others), it is important to discuss complications honestly with PLwD, and enable individuals to make safe choices, with knowledge and access to education without judgement and also facilitate PLwD to be curious about their diabetes (Wright & Phillips, 2017).

DIABETES SELF-MANAGEMENT EDUCATION (DSME)

PLwD would value HCPs asking for feedback if they have been referred to structured education for example – rather than this being a template ticking exercise. Make this a valuable mutual learning experience, to facilitate the HCP to understand the value of education and where best to recommend PLwD to go – signposting appropriately accordingly to the needs of each PLwD, not just to what is delivered or commissioned locally.

Diabetes education is far more than DSME, as much information is accessed online - suggestions of reliable sources of information can help PLwD to define what can be useful to them.

Whilst social media can be useful, it is worth acknowledging the support network PLwD can gain by being in touch digitally, however, this can also work in reverse if an individual is struggling and can feel disempowered also. NHS England (2019) is launching an innovative online education resource for PLwD. These growing online education resources can increase accessibility and access to reliable information.
ENSURING FIDELITY OF THE PROCESS

PLwD value being encouraged to express concerns in a safe, non-judgmental environment. Much has changed in the evidence available and the attitudes to HCP approaches within diabetes care. Recent evidence from 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 PLwD to express their choice for that medication and for HCPs to use open questions seeks to gain feedback and avoid assumptions.

PLwD 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 PLwD. This can be experienced really positively, but also negatively if the HCP does not listen, misses verbal or non-verbal cues or speaks at the PLwD offering them no choice or any chance to offer any feedback. This can occur when HCPs are tired or stressed, or ‘template tick boxing’ and needs recognition to avoid this having a negative and potentially traumatic effect on the PLwD.

CONCLUSION

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

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 PLwD can engage with this without fear of judgment and really focus their consultation to their needs.
References:


• Hello my name is, A guide for more compassionate care, <https://www.hellomynameis.org.uk/>


• Health Professional Education to meet service and individualised needs, www.ideal.diabetes.com


