

Communicating with people at risk of type 2 diabetes: Findings from the Merseyside Impaired Glucose Regulation Pathway Project

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The language in which public health advice is communicated is critical. For people at risk of type 2 diabetes, potential behaviour change and responses to involvement in intervention programmes can be mediated by the language in which the risk of the condition and the offer of intervention are communicated. The authors conducted interviews and mini focus groups as part of the Merseyside Impaired Glucose Regulation (IGR) Pathway to determine the awareness of IGR and type 2 diabetes among people with IGR. The preferences of the responders for the language used by healthcare professionals to discuss their condition and the style of language used during interventions were also investigated.

Impaired glucose regulation (IGR) can be described as a blood glucose level above the normal range but below that required for a diagnosis of type 2 diabetes (Nathan et al, 2007). Compared to people with normal blood glucose, those with IGR are 5–15 times more likely to develop type 2 diabetes (Killoran et al, 2012). For those people at highest risk of developing type 2 diabetes, evidence suggests that modest lifestyle changes can postpone or even prevent the onset of diabetes (Tuomilehto et al, 2001; Knowler et al, 2002). Type 2 diabetes is a major cause of premature mortality in England (Gatineau et al, 2014), so the benefit of providing support for people with IGR to prevent the development of type 2 diabetes is clear to see.

The Merseyside IGR pathway

The Merseyside IGR pathway was developed by a multi-stakeholder group of professionals and patients in Merseyside, and its development and implementation is described in full in *Diabetes and Primary Care* (du Plessis et al, 2015). Briefly, the pathway is designed for people who are identified as being at high risk of developing type 2 diabetes. It is initiated via the NHS Health Check programme

or opportunistically in primary care. The risk factors for type 2 diabetes include obesity, a high blood pressure reading or a positive family history (Department of Health, 2013). Identification of eligible people for the pathway is usually via HbA_{1c} testing, with a result of 42–47 mmol/mol (6–6.5%) confirming IGR, as recommended by the World Health Organization (2011).

After identification, the primary care teams work with the enrolled individuals to explain the meaning of IGR and provide IGR-specific advice and support (e.g. lifestyle literature). At the time of this study, the pathway consisted of an initial assessment; a health trainer to advise and guide behaviour; a personal care plan and goal planner (a set of targets developed and agreed between patient and support worker for healthier living, [e.g. setting achievable weight reduction targets]); lifestyle services including peer group support; and regular monitoring by a GP surgery team. Each individual is supported by primary care colleagues to develop achievable aims.

Aim

The aim of this qualitative study was to utilise insight and engagement from patients not currently

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Article points

1. Type 2 diabetes is a major cause of premature mortality in England, and impaired glucose regulation (IGR) is a strong indicator of risk of type 2 diabetes.
2. Strategies aimed at supporting people with IGR should include tailoring interventions to individuals and setting achievable targets.
3. The language used to describe IGR and its associated risks and the language used to present an intervention service pathway is crucial to the success of the intervention proposal.
4. “Borderline diabetes” is the preferred term for IGR among the cohort interviewed for this research as it suggests individuals can do something about their condition.

Key words

- Communication
- Intervention
- Language

Authors

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Page points

1. The aim of this study was to utilise insight and engagement from individuals currently in the Merseyside Impaired Glucose Regulation pathway to maximise access and to facilitate the uptake of services in the pathway by new eligible patients.
2. Research was conducted through a qualitative study combining face-to-face depth interviews and paired depth interviews, followed by mini focus group sessions of respondents re-recruited from the first stage of interviews.

in the Merseyside IGR pathway to maximise access and facilitate the uptake of services in the pathway by new eligible patients.

The selected group were interviewed on their level of awareness of type 2 diabetes and IGR, and their preferences for the style of intervention and support. Their preferences for the type of language used to describe IGR and the language used to offer information and advice on lifestyle changes and preventive action were also investigated.

Methods

Research was conducted through a qualitative study combining face-to-face depth interviews and paired depth interviews, followed by mini focus group sessions of five respondents re-recruited from the first stage of interviews.

The topic guides were designed and developed in partnership with clinicians and public health professionals for the depth interviews and focus group discussions. The depth interview script covered the following topics: current lifestyle choices; awareness of type 2 diabetes; awareness of personal risk of developing type 2 diabetes; awareness of pre-diabetes; perception and understanding of different terms labelling pre-diabetes (including borderline diabetes); and views on a pre-diabetes service pathway. The focus group script covered the following topics: a recap on participants' recall of the initial interview; assessing views of a potential pre-diabetes pathway in detail; and assessment of communication approaches (formats, language and content). The depth interviews lasted for 1 hour and the focus groups for 2 hours.

The interviews and focus groups were audio-recorded, and findings were analysed inductively using content analysis. Emerging themes were tested and further explored during the second stage of mini focus groups. The Healthy Foundations Life-stage Segmentation Model (Department of Health, 2011) was employed as a specific analytical tool. Healthy Foundations segmentation is a measure of attitudes to health, and of motivation to engage with healthcare initiatives, based on a robust data set. It divides the population into five groups: "unconfident fatalists", "health conscious realists", "balanced compensators", "live for todays" and "hedonistic immortals". Healthy

Foundations segmentation demonstrates that there is a strong correlation between poor motivation and economic deprivation (Department of Health, 2011), and it is a powerful tool for modelling population groups and predicting attitudinal and motivational barriers to engagement with health information and interventions.

Results

The 48 participants were of mixed gender and exhibited risk factors for the development of type 2 diabetes – they were all overweight and reported a mix of unhealthy, high-risk lifestyles, including smoking, drinking above advised limits and physical inactivity. They had a low motivation for self-initiated health behaviour change and had low levels of health literacy. Participants were grouped demographically under National Readership Survey grades. There were 10 participants in the ABC1 grade (equates to middle class) and 38 participants in the C2DE grade (equates to working class), which included all of the ethnic minority respondents.

Healthy Foundations segmentation analysis revealed a strong bias in the data towards two specific segments – "unconfident fatalists" and "live for todays". "Unconfident fatalists" are characterised by low self-esteem and having negative health behaviours and a fatalistic outlook. "Live for todays" hold a short-term view of life and often have chaotic lifestyles and a low resilience in relation to life challenges.

Thirty-six face-to-face depth interviews were conducted: 28 of the participants were believed to be at risk of IGR, and eight people were previously diagnosed with IGR. Twelve paired depth interviews were carried out with ethnic minority group members. Eight mini focus groups were then organised with respondents re-recruited from the first stage.

Research findings indicated the emergence of three main themes:

- Poor awareness of the symptoms of, and lifestyles conducive to, type 2 diabetes.
- Definite views on the preferred elements of intervention service pathways.
- Clear preferences about the language used to communicate the risk of developing type 2 diabetes and offers of intervention.

Poor awareness of type 2 diabetes contributors among participants

Among the participants interviewed and from data collected from the mini focus groups, awareness of type 2 diabetes was poor. In particular, the specific symptoms and health consequences of type 2 diabetes, and the role of healthy eating and physical activity in preventing type 2 diabetes were not generally understood. Respondents typically understood type 2 diabetes to be connected with diet, particularly in relation to sugar intake, but understanding was vague. While respondents understood their own lifestyles were not especially healthy (respondents reported their diets as unhealthy, and understood smoking and alcohol consumption as components of an unhealthy lifestyle), they did not make a direct connection between elements of their lifestyle and the risk of type 2 diabetes. The barriers given for not following a healthy diet were typically expressed in economic terms (e.g. “why is it so expensive to eat healthy?”).

Being overweight or obese was not clearly understood as a risk factor in the onset of type 2 diabetes and, in respect to excess weight, denial and avoidance were observed.

There was confusion about the relationship between IGR and type 2 diabetes (“I would take one look [at the IGR diagnosis] and think I had type 2 diabetes”). Respondents were surprised by the severity of the health consequences of type 2 diabetes, and saw the link to heart disease and stroke as new, and frightening, information.

Participant views on elements of the intervention pathways

There was a positive reaction to the intervention service pathway provided in Merseyside at the time of the interviews, and the key qualities seen as necessary for the service pathway were found to be the following:

- Services should be individually tailored.
- Services should be accessible.
- Services should be specific to the condition.

Respondents also expressed a need for positive encouragement and help in setting themselves achievable targets, both in diet, exercise and enhanced physical activity. Generic messaging about weight loss or achieving a healthy BMI

were perceived as not very motivating for the participants. However, messages focused on a target weight loss of 5% of original body weight was motivating for participants as it appeared more achievable.

Respondents saw the identification of risk as a positive opportunity for behaviour change (“Knowing how you got it, knowing where you are now is the first step to dealing with it”).

Respondents preferred a telephone call specifying the initial concern from the clinician followed by an invitation to an initial assessment. It was important to the interviewees that it was made clear that IGR was not a diagnosis of type 2 diabetes, and who in the medical team they should make the appointment with. A majority of respondents were positive about the initial assessment being with a nurse or healthcare assistant (“I’d feel more comfortable discussing this with the nurse; the doctor is too busy” and “I think doctors are sometimes intimidating and you tend not to tell the truth, whereas a health trainer would relate to you more and understand”). There was clear support for the idea of a goal planner, tailored to the individual, with achievable goals.

Most respondents felt it was important that they were monitored and supported regularly in their attempts to achieve weight loss and healthy eating targets. All understood that this monitoring and support would not come directly from the GP in the Merseyside IGR pathway, and most were positive about the role of the health trainer. Respondents felt it was important that monitoring and support were directed by the clinical team; that is, the onus was not on patients to contact the support service.

Patient involvement in planning their own programme of change followed by proactive monitoring and support were seen by the majority of responders as important factors in motivating them to take a share of the responsibility for their borderline diabetes diagnosis.

Language preferences

From discussing the service pathway with the participants, it became clear that the language used to present the risk of type 2 diabetes should be clear and strong but balanced with positive and optimistic language about the potential for

Page points

1. Data from the interviews and mini focus groups showed that awareness of type 2 diabetes was poor.
2. There was a positive reaction to the intervention service pathway provided in Merseyside at the time of the interviews.
3. Most respondents felt it was important that they were monitored and supported regularly in their attempts to achieve weight loss and healthy eating targets.

Page points

1. The “good news/bad news” approach was generally seen as the best method for engaging attention and encouraging behaviour change.
2. The term “borderline diabetes” suggested to respondents that they could do something about preventing the onset of type 2 diabetes, whereas “pre-diabetes” was seen as implying that type 2 diabetes was inevitable.

prevention through changes to a healthier lifestyle. The “good news/bad news” approach was generally seen as the best method for engaging attention and encouraging behaviour change (“One thing I would pick up on is the good news. You may be able to reduce the instance of stroke and heart disease”). Participants preferred language which was not loaded with medical terminology, and which emphasised the potential for improvement through achievable increments in behaviour change.

“Borderline diabetes”

As part of the interviews and mini focus groups, preferred terms for IGR were tested. There was a marked preference for the use of the term “borderline diabetes” over “pre-diabetes”, and there was considerable disagreement about the third suggested term “high risk of diabetes”. “Borderline diabetes” suggested to respondents that they could do something about preventing the onset of type 2 diabetes, whereas “pre-diabetes” was seen as implying that type 2 diabetes was inevitable. Respondents were split in their opinion of “high risk of diabetes”. Some saw it as a motivating statement, and it was deemed to be particularly useful in communicating IGR to those from black and minority ethnic groups. Other people considered “high risk of diabetes” to be too generic a statement (“We’re all at high risk of something”).

Overall, it was felt that “borderline diabetes” was the best term for communicating IGR, while “high risk of diabetes” would provide a powerful motivating statement in any written or spoken information about the condition. The most engaging full definition of “borderline diabetes” co-created through the research session was as follows:

Borderline diabetes is a serious condition that significantly increases your risk of getting type 2 diabetes. It can also double your chances of suffering from heart disease or stroke.

The good news is that by losing weight, eating healthier and increasing your physical activity you may be able to delay or prevent borderline diabetes from progressing any further. You may even reduce the level of sugar in your blood so you no longer suffer from borderline diabetes.

Language of services available

The language of the clinical team when offering intervention needed to be emotionally supportive and demonstrate empathy with the target audience and their concerns. Acknowledgement of personal circumstances was also reported as important. A clear definition of IGR and type 2 diabetes risk was seen as vital to encouraging involvement in intervention. In particular, respondents wanted to hear a clear message that this was not a diagnosis but a statement of risk.

Discussion

The research findings outlined here clearly indicate that clarity of language and use of positive language are necessary components of a successful intervention programme.

To describe IGR for this cohort, the term pre-diabetes is loaded. It implies an inevitable progression into developed type 2 diabetes and is liable to induce feelings of fatalism and powerlessness. We believe that people who are labelled with pre-diabetes tend to be less likely to be motivated into making positive changes to their lifestyles and less likely to see any such changes as preventive. Given that behaviour change, in particular healthy eating, regular physical activity and exercise, are optimal responses, it is critical that the language used to convey the condition carries a positive message, so that people are encouraged to make changes and understand that those changes can have a real effect. The term “borderline diabetes” was seen much more positively by responders, and thus we believe it is a better use of language to describe IGR. It offers choice and opportunity, and implies a person can do something to prevent the onset of type 2 diabetes through their own efforts, with the help of suitably qualified health carers and the support of their peers.

There is a requirement to link lifestyle choices with the risk of type 2 diabetes among people with IGR, and it follows, therefore, that there is a requirement to make it clear that a healthy lifestyle has a preventive role in respect of diabetes. It makes sense that an intervention is more effective when it is tailored to the specific circumstances, and specific needs, of individuals.

Findings from this study indicate that this

approach will have a positive impact on the population groups who are at high risk of type 2 diabetes, and on those who are least likely to self-initiate changes towards a healthier lifestyle. By using the most appropriate language to engage with people at risk of type 2 diabetes, we can aim to ensure that any gaps in awareness and education about the symptoms and consequences of diabetes can be addressed.

Tailoring the intervention service pathway to the preferences of particular Healthy Foundations patient segments where possible is important in encouraging patient engagement and managing participant expectations.

In terms of service delivery, the intervention toolkit needs to have a mix of elements that are local, personal and specific to ensure individual needs are met. Initial assessment is critical in terms of engaging patients and persuading them to “buy in” to the intervention pathway. Integration and communication between medical and non-medical team elements is important to retain interest and commitment, and setting achievable goals is essential.

Conclusion

Clear patient preferences emerged from the current research. People at risk of diabetes are more likely to respond to information if the language used presents opportunities for change. Terminology that does not present IGR as a definite precursor to type 2 diabetes is more likely to motivate those at risk to enrol in intervention service pathways; using “borderline diabetes” may be the way forward in this respect. Furthermore, an intervention that is properly tailored to the individual’s circumstances encourages involvement even among groups that find self-motivation difficult. If the intervention pathway is properly tailored to the needs and circumstances of the individual and is focused on motivating change and continuing engagement, it can represent a real opportunity for tackling a major public health issue in an innovative and successful way. ■

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