

# THE SIX PRINCIPLES OF GOOD PEER SUPPORT FOR PEOPLE LIVING WITH TYPE 1 DIABETES



# Forewords

Self-management of one's Type 1 Diabetes can be tiring and tough on mental health. A key benefit of peer support is access to the help from peers who also deal with such issues day in, day out.

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. If, as a system, we want to improve chronic disease management, we need to switch our focus from healthcare professionals to consideration of the people with the chronic disease themselves, and peer support must be one of the key areas to target.

As individuals living with Type 1 Diabetes from varying and diverse backgrounds, we feel these six principles provide a solid foundation of what peer support should look like. Our experiences of peer support have allowed us to develop these fundamentals collaboratively, utilising an approach which is inclusive and person-centred. The aim of improved access to peer support is to provide invaluable additional information, and resource, and for people with diabetes to benefit from emotional and practical support and the ability to problem solve and self-manage.

Peer support can provide a space where individuals can express the highs and lows of living with diabetes – whilst feeling supported- and we hope this piece of work will lead to flourishing of such principles to help many, if not all, living with Type 1 Diabetes.

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Shaun Carpenter & Emma Doble  
People living with Type 1 Diabetes

We know that people who lack confidence to self-manage are more than 10 times more likely to access health and care services. And critically we know that personal and population health outcomes are optimised by various supported self-management programmes, which importantly includes peer support.

One of the key points made in the Constitution for the National Health Service is that the NHS belongs to the people. And part of delivery of this mission is to support people to live their best lives, with high quality outcomes for their health and wellbeing.

But to 'mainstream' working in partnership with people requires a shift in culture to empowering people and a recognition that peer support plays a critical part to better support people to self-manage and therefore optimise their healthcare outcomes.

The publication of 'The Six Principles Of Good Peer Support For People Living with Type 1 Diabetes' is particularly well-placed given this context and the recent integration of health and care by the establishment of local Integrated Care Systems (ICS). It has been produced specifically for anyone looking to run or commission a peer support group for those with Type 1 Diabetes.

This document outlines our general support for Peer Support as a part of our commitment to making personalised care business as usual within the NHS, as outlined in the NHS Long Term Plan.

**Aimee Robson**  
Deputy Director, Personalised Care, NHS England

Type 1 Diabetes is challenging - full stop. And make no mistake, those who don't go through the daily incessant nature of it, the unforgiving permanence of it all- perhaps will never quite appreciate how tough it is. In the backdrop of an NHS where workforce pressures abound, we need to remember a long-term condition such as Type 1 Diabetes hinges on three planks- self management, peer support and access to trained professionals. The NHS continues to work at improving self-management, yet in a health system where the individual is mostly dealing with their condition without professional support? Peer support is an under recognised if not underutilised support to improve health.

This piece of work, led by six amazing individuals living with Type 1 Diabetes with support from Juvenile Diabetes Research Foundation and Diabetes UK, is a welcome step forward and hopefully sets the template for peer support being as much a fundamental part of Type 1 Diabetes care as education and technology. It would be amiss not to mention the work done by the Personalised Care team of NHS England- and a big thank you to all else who have contributed.

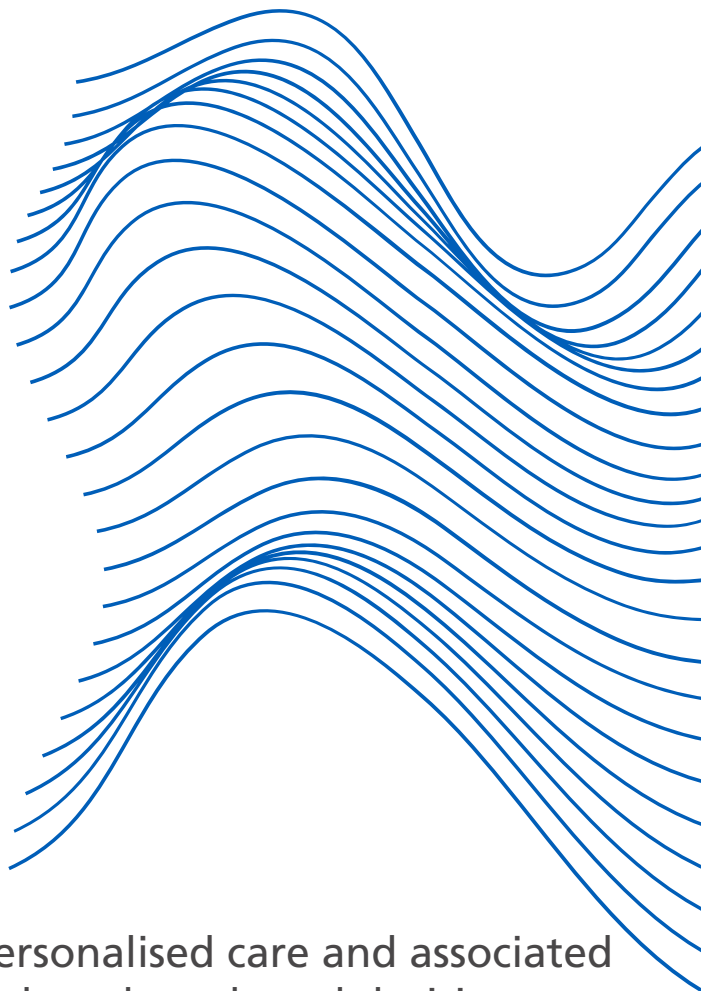
We as health care professionals and commissioners need to understand and appreciate how much those living with Type 1 Diabetes can help us achieve our common goal of better care. In the words of T'Challa "In times of crisis, the wise build bridges; the foolish build barriers". This is our moment in the NHS to build bridges and help the Type 1 Diabetes community come together.

**Partha Kar**  
National Specialty Advisor, Diabetes, NHS England

# INTRODUCTION

Peer support, or people drawing on shared experiences to help each other with knowledge, information and support, is a simple but powerful approach to health and wellbeing.

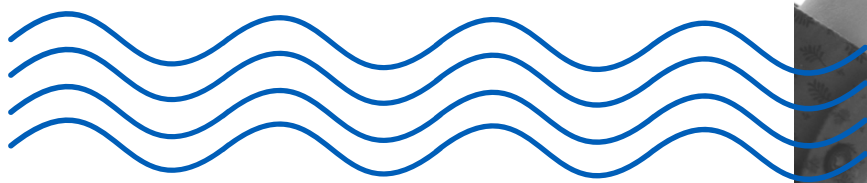
Its value has long been recognised by people and carers, as well as by clinicians. It is particularly valuable for those with long term conditions such as Type 1 Diabetes, as those newly diagnosed can learn from the experiences of others in gaining knowledge skills and confidence, which they often find value in passing on in their turn.



As personalised care and associated models such as shared decision - making and supported self-management become embedded into the mainstream of the NHS, peer support can offer a valuable resource to people and their families and carers enabling them to take ownership of their health and care, ensuring that their voice is at least equal to clinicians in managing their conditions.



To increase credibility among members and potential members of peer support groups; confidence in referring clinicians; and to build a common purpose, peer support groups may wish to sign up to a set of 'standards' or 'principles'. This approach has been taken by other communities – for example the HIV community in 2017 with the National Standards for HIV in peer support. This will let people know what they can expect and, just as importantly, what they can't expect from a peer support group.



## THESE PRINCIPLES ARE:

- Driven by the **shared experiences of people** living with Type 1 Diabetes
- **Reciprocal**, with opportunities for people to 'give and get' as well as to learn from one another
- **Safe and encouraging**, allowing people to share their experiences free from any judgement
- **Accessible and inclusive**, available to everybody with Type 1 Diabetes
- **Person-centred**, taking account of each person strengths, values, needs and feelings
- **Complementary**, working hand in hand with health and social care providers

There is no one right model of peer support and it can take a variety of different forms from online forums, to weekly meetings and in a range of venues from a clinic's office to a coffee shop and include different numbers of people – how the principles will be addressed will depend on all of these factors. However, in its broadest sense,

This document seeks to set out **“what good looks like”** for peer support – or what people should expect from a well functioning group, with a specific focus on Type 1 Diabetes.

# WHO IS THIS DOCUMENT FOR?

This document is for anyone looking to run or commission a Peer Support Group for those with Type 1 Diabetes. It may be read alongside the Peer Support Quality and Implementation Guide, as well as Supported Self Management Summary Guide which provide additional information on implementing peer support.





# WHY AND HOW WE PRODUCED THIS DOCUMENT

NHS England commissioned Diabetes UK and JDRF, along with a stakeholder group including those with lived experience, to lead on this work. Initially the focus was on mapping peer support groups with a view to exploring any 'gaps' in provision. We soon expanded to considering the quality of these groups and how this may be helped with the production of some standards that would provide a basis for groups to sign up to.

We convened a stakeholder group which had experts including people with lived experience who acted as critical friends in the production of these principles.

Next steps include acknowledging the value of peer support and what else we can do together to raise awareness around the value and impact of peer support that can help people to develop their capability and access to tailored support to help them to live well with a long – term condition.

# SCOPE

| What these principles ARE                                                                                                       | What these principles are NOT                                                        |
|---------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------|
| A collaborative approach to what 'good peer support looks like'                                                                 | An exhaustive list of all the considerations, merits and objectives of peer support. |
| A summary of the values that should underpin a peer support group                                                               | Something that is objectively measured/monitored by Diabetes UK/JDRF or NHS England  |
| By signing up to them, a way for peer support groups to advertise their ethos and philosophies to members and potential members | An endorsement of any specific group by Diabetes UK/JDRF or NHS England              |
| A trusted, co-produced set of principles for clinicians to be able to refer people with Type 1 Diabetes                         | A guarantee of the way (or if) any of these values are held by the specific groups   |

**Disclaimer:**

NHS England, JDRF and Diabetes UK cannot guarantee the quality or safety of any peer support group or network. It is recommended that you contact your preferred peer support group or network directly to find out more about their service.

# PRINCIPLES AND RATIONALE

1. Driven by the **shared experiences of people** living with Type 1 Diabetes

## WHY IS THIS IMPORTANT?

The value of good peer support comes from people sharing their experiences, frustrations and successes with others who have been through similar things themselves.

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What does this mean for:

## PEOPLE WITH TYPE 1 DIABETES ACCESSING AND GIVING GROUP SUPPORT AS A GROUP MEMBER

People can share real-world examples of how living with Type 1 Diabetes affects them. They can find reassurance and support from other people in the group who know what it's like to live with the condition.

## PEOPLE GIVING TYPE 1 DIABETES PEER SUPPORT AS A GROUP LEADER / FACILITATOR

Facilitators being able to share their own experiences with confidence will help and encourage others to do the same, whilst being mindful that each person's own experience is unique.

## CLINICIANS AND SERVICE PROVIDERS

Referring people to a group of 'experts by experience' will provide a vital avenue for people to feel confident and supported in living with Type 1 Diabetes.



# PRINCIPLES AND RATIONALE

2. **Reciprocal**, with opportunities for people to 'give and get', as well as to learn from one another

## WHY IS THIS IMPORTANT?

Reciprocal support recognises the mutual benefit of giving and receiving support

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What does this mean for:

## PEOPLE WITH TYPE 1 DIABETES ACCESSING AND GIVING GROUP SUPPORT AS A GROUP MEMBER

All experiences of living with Type 1 Diabetes are valid and no one person is more 'expert' than another. It would be helpful for group members to understand the difference between information and advice.

## PEOPLE GIVING T1D PEER SUPPORT AS A GROUP LEADER / FACILITATOR

The reciprocity of peer support emphasises the importance of creating a flexible space for people to share their experiences and from people to 'give and get' from one another. It is recommended that Facilitators have confidence in leading groups, including the ability to manage group dynamics and potentially difficult discussions.

## CLINICIANS AND SERVICE PROVIDERS

Confidence that people are being referred to an evidence-based, overarching experience that gives meaning and purpose.



# PRINCIPLES AND RATIONALE

## 3. **Safe and encouraging**, enabling people to share their experiences free from any judgement

### WHY IS THIS IMPORTANT?

Peer support should provide people with a safe, non-judgemental environment to be able to talk about their experiences of Type 1 Diabetes.

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What does this mean for:

### PEOPLE WITH TYPE 1 DIABETES ACCESSING AND GIVING GROUP SUPPORT AS A GROUP MEMBER

In listening to others' experiences and building trust and confidence in the peer support group, people should feel safe to share their own experience of living with Type 1 Diabetes. All group members may contribute to and agree common ground rules and boundaries (for example confidentiality) that will enable this trust to be built.

## PEOPLE GIVING TYPE 1 DIABETES PEER SUPPORT AS A GROUP LEADER / FACILITATOR

Peer supporters should create the right conditions for a safe, nurturing, and welcoming environment, enabling and encouraging people living with Type 1 Diabetes to share their own experiences and to learn from others. Group leaders might want to be aware of the benefit of establishing ground rules and / or a group agreement.

## CLINICIANS AND SERVICE PROVIDERS

Confidence in referring people with Type 1 Diabetes to a safe and supportive peer support group.





# PRINCIPLES AND RATIONALE

## 4. Accessible and inclusive, available to everyone with Type 1 Diabetes

### WHY IS THIS IMPORTANT?

Everyone with Type 1 Diabetes should have equal access to peer support.

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What does this mean for:

### PEOPLE WITH TYPE 1 DIABETES ACCESSING AND GIVING GROUP SUPPORT AS A GROUP MEMBER

People can feel confident that they can access their choice of peer support group.

## PEOPLE GIVING TYPE 1 DIABETES PEER SUPPORT AS A GROUP LEADER / FACILITATOR

Clear thought should be given to what would make groups accessible and inclusive e.g. the appropriate language for health literature, physical accessibility and / or cultural or religious considerations. Barriers that might prevent people from accessing support should be mitigated wherever possible.

It is unlikely that any one group or avenue of support will be able to meet the needs of large groups of people, so knowing about and being able to signpost alternative avenues of support is useful.

## CLINICIANS AND SERVICE PROVIDERS

Confidence in referring people to an accessible and inclusive peer support group.



# PRINCIPLES AND RATIONALE

## 5. **Person centred**, taking account of each person's own strengths, values, needs and feelings

### WHY IS THIS IMPORTANT?

Peer support should be focused on each person, their own unique characteristics, and what matters to them.

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What does this mean for:

### PEOPLE WITH TYPE 1 DIABETES ACCESSING AND GIVING GROUP SUPPORT AS A GROUP MEMBER

People with Type 1 Diabetes are seen as a whole person in the context of their own lives and experiences. Good peer support can help people to understand where their existing strengths and assets lie and how they can draw on these to help them manage their day to day lives.

## PEOPLE GIVING TYPE 1 DIABETES PEER SUPPORT AS A GROUP LEADER / FACILITATOR

Good listening skills are implicit in supporting someone to identify their own skills and resources, as well as what is available to them in the community. Good peer support looks outside the peer support group itself to signpost effectively to other services, which meet the needs of each person in the group.

## CLINICIANS AND SERVICE PROVIDERS

Confidence that people are being supported to develop their knowledge, skills and confidence to support their Type 1 Diabetes.



# PRINCIPLES AND RATIONALE

## 6. **Complementary**, working hand in hand with health and social care providers

### WHY IS THIS IMPORTANT?

Good peer support should run alongside existing health and social care provision, enabling holistic provision of services to suit each individual person's needs.

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What does this mean for:

### PEOPLE WITH TYPE 1 DIABETES ACCESSING AND GIVING GROUP SUPPORT AS A GROUP MEMBER

Good peer support is one component in a complete toolkit of care. It provides options, opportunities, and choice for people to live well with Type 1 Diabetes.

## PEOPLE GIVING TYPE 1 DIABETES PEER SUPPORT AS A GROUP LEADER / FACILITATOR

Working in a complementary way means that people will be encouraged to access a range of services that best meet their needs. It recognises that peer support is only one aspect of Type 1 Diabetes management.

## CLINICIANS AND SERVICE PROVIDERS

Confidence in referring to a peer support group to complement the service that they are providing.



## ACKNOWLEDGMENTS

Jo Fitzgerald, NHS England  
Gemma Crabtree, NHS England  
Jo Fewell, NHS England  
Jim Phillips, NHS England  
Jo Wynn, NHS England  
Fiona Campbell, NHS England  
Tabitha Randell, NHS England  
Andrew Broomhead, Diabetes UK  
Dan Farrow, JDRF  
Rageshri Dhairyawan, Barts health  
Garry Brough, Positively UK

