

# Introduction to the toolkit

## Background

Thomas Pocklington Trust (referred to herein as Pocklington) commissions research into a wide range of aspects relating to adults living with sight loss. Although experienced researchers, it is often the case that the research teams we commission to undertake projects have not previously worked with people with sight loss.

The purpose of the toolkit is to share good practice principles about the involvement of adults with sight loss in the research process. It suggests ways in which research teams might ensure that research participants feel fully engaged and involved with the project throughout the process.

Services vary considerably across the UK depending on area and resource availability. The toolkit highlights the most important issues, definitions and divergences so that researchers new to the sight loss sector can begin to build a knowledge base without 'reinventing the wheel'.

People with sight loss interact with Pocklington research in a multiplicity of roles and not just as research participants. Therefore, practical guidelines within the toolkit on producing accessible materials and organising events for people with sight loss have relevance for the research project more widely.

It is important to note that the toolkit makes suggestions and explores options. A one size fits all approach is unrealistic and undesirable. The level, type and experience of sight loss are hugely variable.

The chapters are provided as separate documents as they relate to different stages of the research process. The titles of each are as follows:

Chapter One: Background information about sight loss

Chapter Two: Policies and Strategies

Chapter Three: Recruiting and engaging research participants

Chapter Four: Collecting data from people with sight loss

Chapter Five: Project Advisory Groups  
Chapter Six: Producing accessible materials  
Chapter Seven: Dissemination and feedback

## Methodology

This toolkit has been informed by interviews with people in the sight loss sector, such as individuals within the Research and Empowerment teams in Pocklington and other sensory loss organisations. Researchers who specialise in service user involvement have offered their guidance on how to make research accessible and inclusive. Researchers who have previously undertaken Pocklington-commissioned projects have provided comments, feedback and advice in reflection of their experiences of working with people with sight loss as research participants.

## Acknowledgements

This toolkit was informed by many individuals who kindly gave their time to offer guidance, feedback and advice.

Dr Graeme Douglas, Dr Liz Ellis, Dr Wulf Livingston, Dr Meridith Griffin, Dr Amy Burton, Dr Hannah Morgan, Tony Scott, Ennis Killip, Jenny Pearce.

Kat Hogg (Guide Dogs), Amanda Reeves (Macular Society), Sujata Ray (Age UK), Dr Anna McGee (Sense), Shaun Leamon (RNIB), John Slade (RNIB), Dr James Pickett (Alzheimers UK), Dr Chris Wood (Action on Hearing Loss), Philly Hare (Joseph Rowntree Foundation).

All colleagues at Pocklington, with special thanks to Dr Lynn Watson, Pamela Lacy, Deborah Brown, Charlotte Knight, Lydia Hardwick, Roy Smith MBE, Lindsay Towers, James Austin, Martin Sigsworth, Will Thornton and Odette Battarel.

Authors: Katie Simkins, Dr Catherine Dennison and Sarah Buchanan