

<b>Consumer involvement in diabetes living guidelines</b>		
The research is being carried out by the following researchers:		
<b>Role</b>	<b>Name</b>	<b>Organisation</b>
Principal investigator	A/Prof Sophie Hill	Centre for Health Communication and Participation, La Trobe University
Co-investigator	Dr Bronwen Merner	Centre for Health Communication and Participation, La Trobe University
<b>Research funder</b>	This research has received \$31,048 from the La Trobe University Building Healthy Communities Research Focus Area.	

### 1. What is the study about?

You are invited to participate in a study of consumer involvement in diabetes living guidelines. Diabetes living guidelines are evidence-based statements that include recommendations to help healthcare professionals and consumers make decisions about diabetes-related care. Living guidelines are updated as soon as important new research is published which ensures health professionals and consumers have access to the most up-to-date information. They are different to “standard” diabetes guidelines which are updated every three to five years.

We hope to learn how consumers can be involved in the development of diabetes living guidelines.

Your contact details were obtained from either of the following:

1. A recommendation through our professional networks.
2. You contacted us to express interest in participating in response to an advertisement about the project.

### 2. Do I have to participate?

Being part of this study is voluntary. If you want to be part of the study we ask that you read the information below carefully and ask us any questions.

You can read the information below and decide at the end if you do not want to participate. If you decide not to participate this won't affect your relationship with La Trobe University or any other listed organisation.

### 3. Who is being asked to participate?

You have been asked to participate because you:

- have experience as a consumer representative in health research, guideline development or health service design; AND/OR
- have lived experience with diabetes; AND
- are interested in exploring opportunities for consumers to be more involved in the development of diabetes living guidelines; AND
- live in Australia; AND
- have access to a mobile phone, tablet, desktop or laptop computer with internet connection; AND
- are able to participate in a 90-minute online forum conducted in English.

Unfortunately, you will not be able to participate if you:

- are aged under 18 years
- cannot provide informed consent for participation in the research

### 4. What will I be asked to do?

If you want to take part in this study, we will ask you to participate in a 90 minute online deliberative forum with other consumers and researchers. During the forum, we will ask for your views about different methods for involving consumers in living diabetes guidelines, and support required to facilitate consumer involvement.

Prior to the forum, we will ask you to read a background paper (which will be emailed or posted to you in advance) that includes information and resources about the process for developing living guidelines. The discussion questions for the

forum will also be included. It will take 40 minutes of your time to read the background paper, explore the resources and prepare your responses to the forum questions.

We will also ask you to complete a pre- and post- survey online about your previous consumer involvement experiences (if any), knowledge of the living guideline process, expectations of the deliberative forum and whether your expectations were met. It will take 10 minutes of your time to complete each of the two surveys.

In total, it will take 2.5 hours of your time to be part of this study. In recognition of your consumer expertise and the value you bring to this project, you will receive a sitting fee (fee for service) for your participation of \$150. This sitting fee is based on the [Safer Care Victoria guide to consumer remuneration](#).

#### 5. What are the benefits?

There are two benefits of you taking part in this study. They are that you may increase your understanding of how consumers can work better with researchers to develop diabetes living guidelines and also the opportunity to network with other consumers and researchers.

The expected benefit to society in general is the potential for a wider range of expertise to be included in the development of living guidelines. This may lead to guidelines that are more relevant and grounded in the needs of society.

#### 6. What are the risks?

With any study there are (1) risks we know about, (2) risks we don't know about and (3) risks we don't expect. If you experience something that you aren't sure about, please contact us immediately so we can discuss the best way to manage your concerns.

Name/Organisation	Position	Telephone	Email
A/Prof Sophie Hill, Centre for Health Communication and Participation, La Trobe University	Head, Centre for Health Communication and Participation	(03) 9479 1941	Sophie.hill@latrobe.edu.au

We have listed the risks we know about below. This will help you decide if you want to be part of the study.

- There is a very small risk you may experience psychological discomfort discussing your lived experience of diabetes (if relevant) during the forum.

#### 7. What will happen to information about me?

We will **collect** information about you in ways that will reveal who you are.

We will **store** information about you in ways that will not reveal who you are.

We will **publish** information about you in ways that will not be identified in any type of publication from this study.

We will **keep** your information for five years after the project is completed. After this time we will destroy all of your data.

The storage, transfer and destruction of your data will be undertaken in accordance with the [Research Data Management Policy https://policies.latrobe.edu.au/document/view.php?id=106/](https://policies.latrobe.edu.au/document/view.php?id=106/).

The personal information you provide will be handled in accordance with applicable privacy laws, any health information collected will be handled in accordance with the Health Records Act 2001 (Vic). Subject to any exceptions in relevant laws, you have the right to access and correct your personal information by contacting the research team.

#### 8. Will I hear about the results of the study?

We will let you know about the results of the study by sending you a draft summary of the deliberative forums via email or post (whichever is easiest for you). You will be invited to contribute to this report if you want to, but you do not have to.

We may also invite you to co-author research publications arising from this project including academic articles and presentations.

#### 9. What if I change my mind?

You can choose to no longer be part of the study at any time until two weeks following the collection of your data. You can let us know by:

1. Completing the 'Withdrawal of Consent Form' (provided at the end of this document);
2. Calling us; or
3. Emailing us

Your decision to withdraw at any point will **not** affect your relationship with La Trobe University or any other organisation listed.

When you withdraw we will stop asking you for information. Any identifiable information about you will be withdrawn from the research study. However, once the results have been analysed we can only withdraw information, such as your name and contact details. If results haven't been analysed you can choose if we use those results or not.

#### 10. Who can I contact for questions or want more information?

If you would like to speak to us, please use the contact details below:

Name/Organisation	Position	Telephone	Email
Bronwen Merner, Centre for Health Communication and Participation, La Trobe University	Research Fellow	+61 3 9479 5327	b.merner@latrobe.edu.au

#### 11. What if I have a complaint?

If you have a complaint about any part of this study, please contact:

Ethics Reference Number	Position	Telephone	Email
HEC20136	Senior Research Ethics Officer	+61 3 9479 1443	<a href="mailto:humanethics@latrobe.edu.au">humanethics@latrobe.edu.au</a>

**Consent Form – Declaration by Participant**

I (the participant) have read (or, where appropriate, have had read to me) and understood the participant information statement, and any questions have been answered to my satisfaction. I agree to participate in the study, I know I can withdraw at any time until [four weeks] following the collection of my data. I agree information provided by me or with my permission during the project may be included in a thesis, presentation and published in journals on the condition that I cannot be identified.

I would like my information collected for this research study to be:

- Only used for this specific study;  
 Used for future related studies;

I agree to have the deliberative forum audio recorded

I would like to receive a copy of the results via email or post. I have provided my details below and ask that they only be used for this purpose and not stored with my information or for future contact.

Name	Email (optional)	Postal address (optional)

**Participant Signature**

I have received a signed copy of the Participant Information Statement and Consent Form to keep

Participant's printed name	
Participant's signature	
Date	

**Declaration by Researcher**

- I have given a verbal explanation of the study, what it involves, and the risks and I believe the participant has understood;  
 I am a person qualified to explain the study, the risks and answer questions

Researcher's printed name	
Researcher's signature	
Date	

\* All parties must sign and date their own signature

**Withdrawal of Consent**

I wish to withdraw my consent to participate in this study. I understand withdrawal will not affect my relationship with La Trobe University or any other organisation or professionals listed in the Participant Information Statement. I understand the researchers cannot withdraw my information once it has been collected as part of a deliberative forum.

**I understand my information will be withdrawn as outlined below:**

- ✓ Any identifiable information about me will be withdrawn from the study
- ✓ The researchers will withdraw my contact details so I cannot be contacted by them in the future studies unless I have given separate consent for my details to be kept in a participant registry.
- ✓ The researchers cannot withdraw my information once it has been analysed, and/or collected as part of a deliberative forum.

*\*\*if you have consented for your contact details to be included in a participant registry you will need to contact the registry staff directly to withdraw your details.*

**Participant Signature**

Participant's printed name	
Participant's signature	
Date	

**Please forward this form to:**

CI Name	Sophie Hill
Email	Sophie.hill@latrobe.edu.au
Phone	(03) 9479 1941
Postal Address	Centre for Health Communication and Participation, La Trobe University, Bundoora 3086