



## An invitation to join the Priority Setting Partnership (PSP) in coeliac disease

Coeliac UK is the charity for people who need to live without gluten. We provide independent, trustworthy advice and support, strive for better gluten free food in more places and fund crucial research to manage the impacts of gluten and find answers to coeliac disease.

Coeliac UK, with the support of the James Lind Alliance, is launching a priority setting partnership (PSP) in coeliac disease and would like to invite you to become a partner in the PSP to help us find out what research would make a difference to people living with coeliac disease, their carers and health professionals.

## What is a PSP?

The <u>James Lind Alliance</u> (JLA) is a non-profit making initiative bringing patients, carers and clinicians together in PSPs. These partnerships identify and prioritise uncertainties, or 'unanswered questions', about specific medical conditions.

The PSP into coeliac disease is funded by Coeliac UK.

The aim is to identify unanswered questions about coeliac disease, to form a list of top ten questions for researchers to answer. This process will help ensure that research addresses the questions that are of most importance to those affected by the condition.

## What are we asking you to do?

By becoming a partner you will be kept informed about the PSP and you can show your support by:

- completing the survey at <a href="https://www.surveymonkey.co.uk/r/coeliacresearch">https://www.surveymonkey.co.uk/r/coeliacresearch</a> (go live date, 1 June 2017)
- adding the survey link to your website
- circulating the survey (or a link to the survey) by email or other channels to encourage patients, carers, colleagues and support networks to complete it
- tweeting about the survey using #coeliacresearch being sure to link to the survey in the tweet
- keeping in touch with the project so that you can be invited to help in the next stage of prioritising the questions that are received. Whether you have taken part in the first survey or not, you can still help us by voting on which of the questions raised should be a priority.

## What do I need to do now?

If you would like to be involved, please email <a href="mailto:katie.stokes@coeliac.org.uk">katie.stokes@coeliac.org.uk</a>

If you are an organisation that would like to show your support of the PSP by including your logo on our website, please include it with your email reply.

For more information, please see our website <a href="www.coeliac.org.uk/researchpriorities">www.coeliac.org.uk/researchpriorities</a>

We look forward to hearing from you.