

Coeliac UK strategy 2020–2025

The Last 10 Years

In 2011 we published an ambitious 10 year strategy to take the charity through to 2020. We identified the step changes needed to improve the lives of people living with coeliac disease and gluten free.

We set out to achieve these key targets:

- increase the numbers with coeliac disease properly diagnosed – from 12% to two thirds.
- reduce the time to diagnosis by one half
- nine out 10 healthcare professionals applying national care standards
- gluten free foods found in all supermarkets regardless of size and location
- gluten free foods which are as nutritious as their gluten containing counterparts
- gluten free dishes available in wherever you eat outside of home and clearly labelled
- increase research into coeliac disease with financial commitment from the charity and the creation of an international fund with our sister charities in Europe.

Much has been achieved with the enthusiastic backing of our members and supporters.

Living well gluten free has never been easier

Our success in making living gluten free easier exceeded all our expectations. In 2009 the value of the gluten free market in the UK was £93m and the latest estimate for 2018 was £394m. The evidence of this growth is there for all to see in the expanded shelf space given over to gluten free, with innovations in fresh bread and ready meals and improvements in quality overall.

Equally, the ability to eat out is transformed. In 2011 there was no legal requirement to label allergens in catering. Although the charity had worked with catering institutions to develop awareness of the demand for gluten free, its impact was not felt on the high street. Today the charity's catering accreditation is held by eight of the top 20 high street chains and gluten free options are expected by many consumers.

More people diagnosed than ever before

There are also improvements in diagnosis. The last available data for 2015 showed 30% of people with coeliac disease were diagnosed. However, time to diagnosis does not appear to have shortened (13 years) and the numbers previously diagnosed with IBS have not halved as we had hoped.

Meanwhile, the healthcare people experience has changed. After diagnosis, most patients would continue to attend hospital for their care in gastroenterology/dietetic clinics. However, change was already happening then, and now most are monitored in primary care or, more likely, not seen at all. Changes in the way people are diagnosed with fewer and fewer biopsies being part of the diagnosis process, mean that there is a continuing drive away from specialist care in hospitals.

Research accelerates

The charity has continued to play a leading role in the UK, funding foundational research:

- changing understanding of the genetic basis of coeliac disease showing clear links to other autoimmune diseases especially type I diabetes
- providing clear evidence of neurological symptoms of coeliac disease and developing a new specific blood test to help its diagnosis
- identifying the most toxic elements of gluten which underpins the development of a vaccine for the disease.

We also bring together and nurture those involved in research in coeliac disease and gluten free foods through conferences and networks. In 2017 we launched a Research Fund Appeal to raise £5m and attracting new money and new researchers into the area as a result.

Progress against 2010-2020 Strategy

We've made good progress against most of the targets that we set ourselves in 2011.

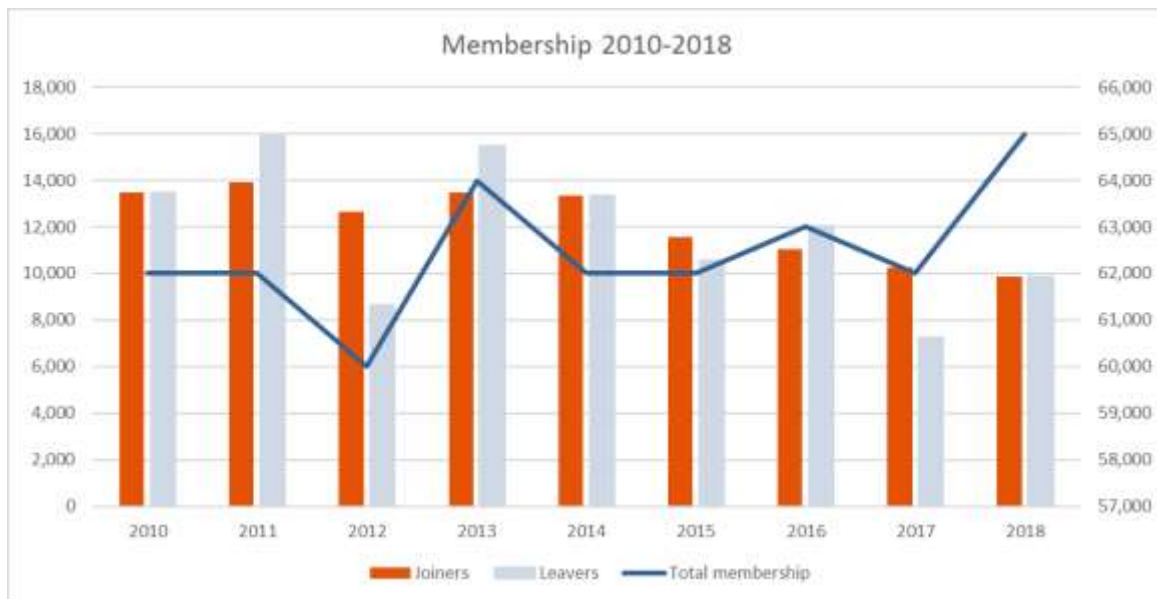
Strategic Aim	Progress
Authoritative support and high quality services	Green
Accelerating the rate of diagnosis and uniformly high quality management	Red
Improving access to a wider range of good quality products	Green
More choice on more menus	Green
Effective use of medical funds and better capacity to build an evidence base	Green
Resources in line with strategic direction and value for money	Yellow

Diagnosis rates, gluten-free prescribing and care standards have been difficult to influence in the NHS given the many demands on their funding and priorities. We have endeavoured to maintain a voice for the coeliac community at the highest levels. Ultimately, we are not the decision makers within the NHS and we compete with many other communities fighting to get the support that they need.

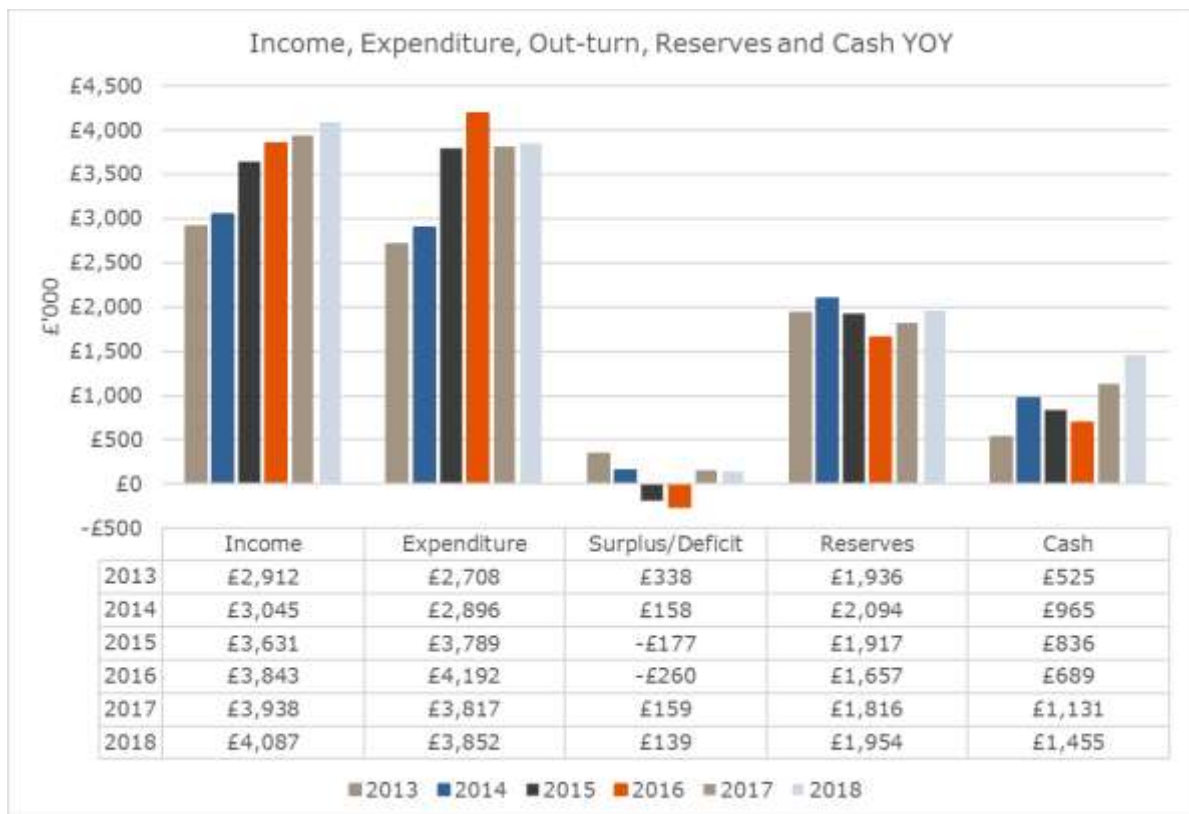
Overall, our financial position remains strong. We are fortunate not to rely on Government funding in this uncertain economic environment, however, in recent months it has been more challenging to secure the income we had anticipated from commercial partners and trusts/grants. This needs to be addressed going forward if we are going to expand our charitable impact.

Our Performance and Impact

Membership has remained relatively static over the past 8 years with an average of 62.5k. It currently stands at over 65k the highest level over the period. Although the total number of members is currently growing, the number of new members joining has been in decline since 2014 which is a concern if we do not turn this around.



Our income has grown by 40% (33% excluding legacy income, and Innovate grant) Expenditure has grown by 42% (35% excluding research grants). Total reserves increased in 2018 due to a £254k net Innovate grant. Overall, the underlying trend requires us to rebalance income vs expenditure so as to retain an appropriate reserves level going forward.



Making a Tangible Difference

We know that we make a difference and that over the past 10 years there have been some significant highlights from our work. These include:

Increasing awareness

- >80% of UK population are aware of Coeliac Disease
- #coeliacawareness week launched 2015 - 10 million impressions in 2019

Safer eating

- Food and drink guide - 150k products
- Gluten Free Venue Accreditation - >3,000 sites
- XGTM >60% trust the trademark more than the gf claim alone – >19,000 products
- Award winning Gluten Free Food Checker app

Policy influencing

- Defended prescriptions – flour mixes and bread still available
- Expert input to labelling legislation

Innovative Research

- Research Fund – raising £5m
- Association of Medical Research Charities backing increases credibility and funding options
- Research to develop better diagnostics, understand related conditions, and measure safe food preparation

Overall, performance has been strong and we have managed to make significant advances on most elements of the strategy. Our financial position is good, but at risk of eroding, and our membership stable. There is an opportunity to further increase our reach and impact. This will strengthen our financial position and will be the main focus of the next phase of the strategy.

Our Market

Coeliac UK operates in two distinct but related markets to deliver our charitable objects:

Healthcare

- Managing Coeliac Condition (CC)* - recognising the medical aspect of CC and working to improve health outcomes through increasing diagnosis and knowledge

Living Gluten Free

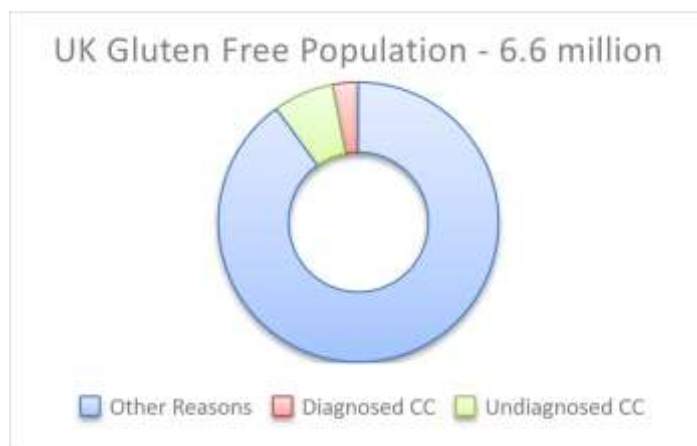
- Recognising the individual choices consumers make to improve their health through changes in diet – reducing or eliminating gluten

*Coeliac Condition includes Gluten Enteropathy, Dermatitis Herpetiformis and any medical condition akin thereto.

In the case of CC, there is an overlap in these two markets. At Coeliac UK, the expertise we have in managing a gluten free diet allows us to:

- Support people with CC (whether diagnosed or not) to live more healthy lives
- Raise awareness of CC to a wider audience for diagnosis, improved care and income generation

We know that we are only currently reaching around 10-15% of the coeliac market and 1% of people living gluten free. This gives us a major opportunity for growth.



Our Continuing Purpose

Although there have been significant developments in the environment in which we operate, we strive to remain as relevant to our beneficiaries as we did over 50 years ago.

Updated Charitable Objects

In considering our future plans, we propose to update the wording of our charitable objects with the Charity Commission to simplify the language and ensure that it give us an appropriate framework within which to operate. We believe that this does not materially affect the focus of our work and remains true to the original intent at the foundation of the charity. The proposed wording is:

- to improve the wellbeing and outcomes of people affected by Coeliac Condition*
- to increase awareness and knowledge of Coeliac Condition
- to improve care and choice for those with Coeliac Condition
- to promote research into the nature, causes, alleviation, treatment and cure of Coeliac Condition

*Coeliac Condition includes Gluten Enteropathy, Dermatitis Herpetiformis and any medical condition akin thereto.

This proposal will be put to our members for approval at the AGM in 2020.

Our Vision

'No life limited by gluten'

This vision remains relevant and strong and will take us to 2025 so we do not propose to change it.

Our Mission

In a similar way to our charitable objects we have slightly updated our mission statement to make the intent clearer. This now reads:

'We will improve the lives of people who can't eat gluten, by:

- providing the, evidence based, independent, expert information and support people need
- being the expert voice within the gluten free community
- being a strong advocate for better diagnosis of coeliac disease, better care, and better access to gluten free food in and out of the home
- investing in research and services to make life better for people who can't eat gluten – and one day overcoming coeliac disease'

Our Values

*We are **informed**.* Our work is backed by evidence, so we can be a trusted voice, advocate and partner for our community.

*We are **independent**.* Everything we say and do is based on achieving the best outcome for our community, and only that. We never let relationships with business, government or others get in the way.

*We are **illuminating**.* We have a huge amount of expert knowledge available to us - but we make it clear and simple, and prioritise what people need when they need it most. That is how we change people's lives.

Looking ahead

We know that many of the original challenges of coeliac condition are still there and new ones have arisen.

Diagnosis rates for coeliac condition remain too low. We've come to understand more about the potential negative effects of gluten ingestion and the different forms of coeliac condition. The financial pressure on the NHS impacts the diagnosis and care of coeliac disease, most notably by the reduction of availability of gluten free prescribing. New ways of accessing healthcare directly are emerging using digital technology.

Consumer Trends

According to the organisation Trendwatching, we should consider five main consumer trends in the design of our future strategy and services:

Self Improvement

- The trend to use new technology and other innovations to improve health and well-being eg personalised sushi to address nutritional deficiencies

Relevance

- The desire for experiences that identify you and your needs as an individual eg Spotify weekly personalised playlist and facial recognition digital billboards

Control

- The recognition that personal data has value and its use should be controlled by the individual eg supermarkets giving access to personal shopping data/GDPR

Connection

- The use of technology to enhance (or replace) face to face relationships eg robotic pet duck used in children's cancer ward/intuitive chat bots

Positive Impact – Open Source Solutions

- Collaborations that will enable us to solve societal/environmental issues or make improvements to humanity more effectively than a single organisation eg Ford/Uber/Lyft sharing transport data to improve routing and reduce congestion

Strategy Design Principles

We have applied the following design principles for our new strategy. The new strategy should be:

- Bold/brave
- Innovative/forward looking
- Beneficiary-centric
- Simple/clear
- Inspiring
- Measurable

2020-2025 Strategic Themes and 2025 Targets

Our core purpose has not changed, and our next 5 year strategy will continue to focus on delivering against our current charitable objects, vision and mission. We are ambitious on behalf of our beneficiaries and want to grow our charitable impact.

We know that to move forward successfully, we need to work hard to keep a sustainable income base. We will continue to focus on our three key funding sources (membership, fundraising and commercial) but will improve our value proposition to each, leveraging new resource, innovative thinking and best practice to make a step change.

We will manage costs carefully and continue to measure ROI to decide where best to invest the precious resources we have.

Regular and effective measurement and tracking will be key to ensuring we know what is working and what is not. We will invest the time to make sure we have the right information to respond in a timely manner to any upturns/downturns that we see.

Over the next 5 years we have 5 strategic themes:

- Increase our reach to more people impacted by coeliac condition and related disorders (Reach)
 - 400k actively engaged individuals
 - 50% awareness of Coeliac UK
 - 50% of coeliacs diagnosed
- Improve the patient/member experience of our beneficiaries (Experience)
 - 150 Coeliac UK "care standards" awarded
 - Net promoter score of >50 for key services

- Grow partnerships and income to help us increase our charitable impact (Partnerships)
 - £3.5m value
- Support and share research that will positively change health outcomes for our beneficiaries (Research)
 - Improve diagnosis
 - Improve management and care
 - Understand cause/effects
- Be world leaders in the support of people affected by coeliac condition (Global Leaders)
 - Launch international associations of coeliac societies
 - Launch global accreditation & licensing system
 - Launch global research programme

Defining and measuring 400k “Actively Engaged”

The key reasons for wanting to extend our reach include:

- Being able to have a positive impact on more beneficiaries
- Demonstrating a greater impact to potential donors/partners
- Providing potential access to a wider audience for partners
- Providing potential access to a wider patient group for research/healthcare professionals

For this reason, we have defined the audience of 400k “actively engaged” be restricted to those people with or supporting people with coeliac condition and other people choosing to live gluten free who benefit from our services. A subset of this group will be our members and volunteers.

“Active Engagement” is defined as individuals who we have permission to contact and or have communicated with/about us, downloaded or shared content digitally in the past 24 months.

We are still refining our measurement and reporting mechanisms to track this number. Our current estimate is between 75-100k. It’s a challenging target for 2025 but with a ‘digital first’ mentality and some new innovative approaches we believe that it’s one we can achieve.

Making it real

We have already stress tested the relevance of the new strategy during our 2020/21 business planning process. The targets, milestones and budget that we have set for 2020 are fully aligned with our longer term strategic aims and can be found in the 2020/21 Business Plan.

The entire Senior Management team of Coeliac UK have been fully involved in the creation of the new strategy and input has been included from staff, members, volunteers, and our Board of Governors.

This is our strategy. We are excited about our future, we hope you are too.