

**PARKINSON'S<sup>UK</sup>**  
**CHANGE ATTITUDES.**  
**FIND A CURE.**  
**JOIN US.**

# **2015-19 Strategy results**

# Introduction

The 2015 - 19 Parkinson's UK strategy was structured around 3 main themes, each of which had targets set against them. These were:

## **Better Treatments and a Cure, Faster**

- There will be 2-4 potential treatments in lab testing, plus 2-4 treatments in Phase I, II or III clinical trials (being tested with people with Parkinson's).
- We will have fixed 4 big problems that stop international pharma companies investing in Parkinson's research.

## **Quality Services as Standard**

- We will deliver a 25% improvement in the quality of Parkinson's services and reduce the gap between the best and poorest quality services by 25%.
- 90% of people will be able to see a Parkinson's nurse, and 70% of people will be able to see specialist therapists.
- 80% of people will be signposted to Parkinson's UK when they are diagnosed.

## **Empowerment to Take Control**

- There will be a 12% increase in the sense of control among people with Parkinson's
- 50% of the public will recognise Parkinson's as a serious health issue, and will have heard of Parkinson's UK.

We also set an income generation target of £181 million over 5 years.

The following slides give a brief summary of how we performed against these 8 targets.

Theme	Target	Result
Better Treatments and Cure, Faster	There will be 2-4 potential treatments in lab testing, plus 2-4 treatments in Phase I, II or III clinical trials (being tested with people with Parkinson's).	Fully met
	We will have fixed 4 big problems that stop international pharma companies investing in Parkinson's research.	Fully met
Quality Services as Standard	We will deliver a 25% improvement in the quality of Parkinson's services and reduce the gap between the best and poorest quality services by 25%.	23% improvement* 16% reduction in the *gap (but overall uplift)
	90% of people will be able to see a Parkinson's nurse, and 70% of people will be able to see specialist therapists.	Parkinson's Nurse 89%* Occupational therapist 54% Physio 66% Speech & language therapist 48%
	80% of people will be signposted to Parkinson's UK when they are diagnosed.	87%
Empowerment to Take Control	There will be a 12% increase in the sense of control among people with Parkinson's.	No change
	50% of the public will recognise Parkinson's as a serious health issue, and will have heard of Parkinson's UK (revised to 62% in 2018).	67% charity recognition 62% condition awareness
Funding Our Activities	We will inspire people to raise £181m over 5 years, to fund our vital work improving care, treatments and quality of life.	£178m

# How did we achieve these results?

- We launched the [Virtual Biotech](#) and the [Excellence Network](#) during the 2015-19 strategy period. Results show that the Virtual Biotech helped us meet our goals, and that the Excellence Network made good progress in a challenging external environment, but we fell short of our ambitions for Parkinson's health services so have rolled this ambition over into the new strategy to build on the good start we made
- We delivered information and support to 28,500 people in 2019 alone, through our helpline and local advisor service, and helped people access over £1m in benefits.
- We also developed the charity itself over the course of 5 years, coming up with new ideas and initiatives that we hadn't even considered in 2014. This includes personalised relationships (now rolled into Parkinson's Connect), exercise and physical activity, Team Parkinson's and digital transformation - many of these are now front of stage in our new 2020-24 strategy.
- This gives us confidence that we can be flexible in how we deliver [our new strategy](#) and that we can build on our successes to deliver transformational change

# Better Treatments and a Cure, Faster

## 2-4 potential treatments in lab testing. Fully Met

Through our Virtual Biotech programme we have supported 4 projects which by the end of 2019 had each created 1 or more novel chemical structures that is currently in testing and development as a possible new treatment for Parkinson's. These are:

- VB Project 1 - Keapstone Therapeutics (small molecule Keap1-Nrf2 inhibitor for disease modification)
- VB Project 3 - "Selcia" small molecule for disease modification
- VB Project 6 - NRG Therapeutics small molecule for disease modification
- VB Project 7 - "Project Calluna" small molecule for disease modification

Also relevant to this KPI is VB Project 2 - Neurolix, where our funding allowed the company to prepare for clinical testing a small molecule for symptomatic treatment of levodopa-induced dyskinesia, by completing the nonclinical development and regulatory submission for initiation of a first-in-patient trial.

## 2-4 treatments in Phase I, II or III clinical trials. Fully met

Our support meant 3 potential new treatments could move forward in the clinical stage in the 2015-2019 period. It should be noted that the GDNF trial failed to achieve the desired outcome for trial participants.

- The [GDNF trial](#), initiated in 2014, was conducted mostly in 2015-2016 with funding from Parkinson's UK (that included a significant contribution from Cure Parkinson's Trust) and MedGenesis Therapeutix. Despite the bravery of 42 volunteers who underwent extensive brain surgery to support the trial, the results were not clearcut. The positive effect of GDNF on some participants offers promising signs that it may be possible to restore the cells damaged in Parkinson's. The trial has proved that delivering a therapy in this way is feasible and acceptable to patients and it has shown that it's possible to deliver drugs with precision to the brain. The outcome of the study has helped us to refine how we set our future goals for success in research projects for the next 5 year period.
- Parkinson's UK awarded funding for trials of cannabidiol for Parkinson's psychosis (King's), and ondansetron for hallucinations in Parkinson's (UCL) in 2018 and 2019. Regulatory and logistical work began on both studies in 2019, although the enrollment of the first patients in both studies will not occur until after the ongoing coronavirus emergency.
- Our support to Bristol University in 2013-2014 led to publication in 2016 of evidence supporting the use of rivastigmine as a symptomatic treatment to reduce falls in Parkinson's. This has resulted in the funding by the [National Institute for Health Research of the CHIEF-PD](#) study.

# We will have fixed 4 big problems that stop international pharma companies investing in Parkinson's research. Fully met

Through our leadership role in the [Critical Path for Parkinson's](#) consortium and studies that we have funded, we have found solutions that address some of the difficulties inherent in clinical trials in a condition like Parkinson's.

1. Selecting the right participants for trials: Qualification of Datscan as an enrichment tool for clinical trials by our Critical Path for Parkinson's consortium.
2. Recruiting to clinical trials to time and target: Parkinson's [UK's Take Part Hub](#) and [Research Support Network](#) both bring people more efficiently to clinical trials appropriate to them.
3. Demonstrating treatments are slowing/stopping progression of Parkinson's: PAMiR - project headed by Prof Auer - developed 4 MRI modalities which can diagnose and track the progression of Parkinson's.
4. Lack of tools for planning clinical trials: Patient stratification developed with our funding in the [Tracking-PD](#) and [Oxford Parkinson's Disease Centre](#) cohorts studies, which can be utilised in clinical trials.



# Quality Services as Standard

## Note on data sources

The information in the following 4 slides (all quality services as standard measures and the first measure in empowerment to take control) have been taken either from the patient reported experience measure (PREM) element of the bi-annual [UK Parkinson's Clinical Audit](#) or the annual Your Life Your Services (YLYS) survey.

The PREM dataset is our most comprehensive one so we use it as our headline figure. However, it should be noted that because data is collected through health care services which engage with us, it tends to give a more positive view of care quality. Your Life Your Services also includes people using services that don't engage with us and therefore tends to be less positive. We have included data from it where appropriate for reference.

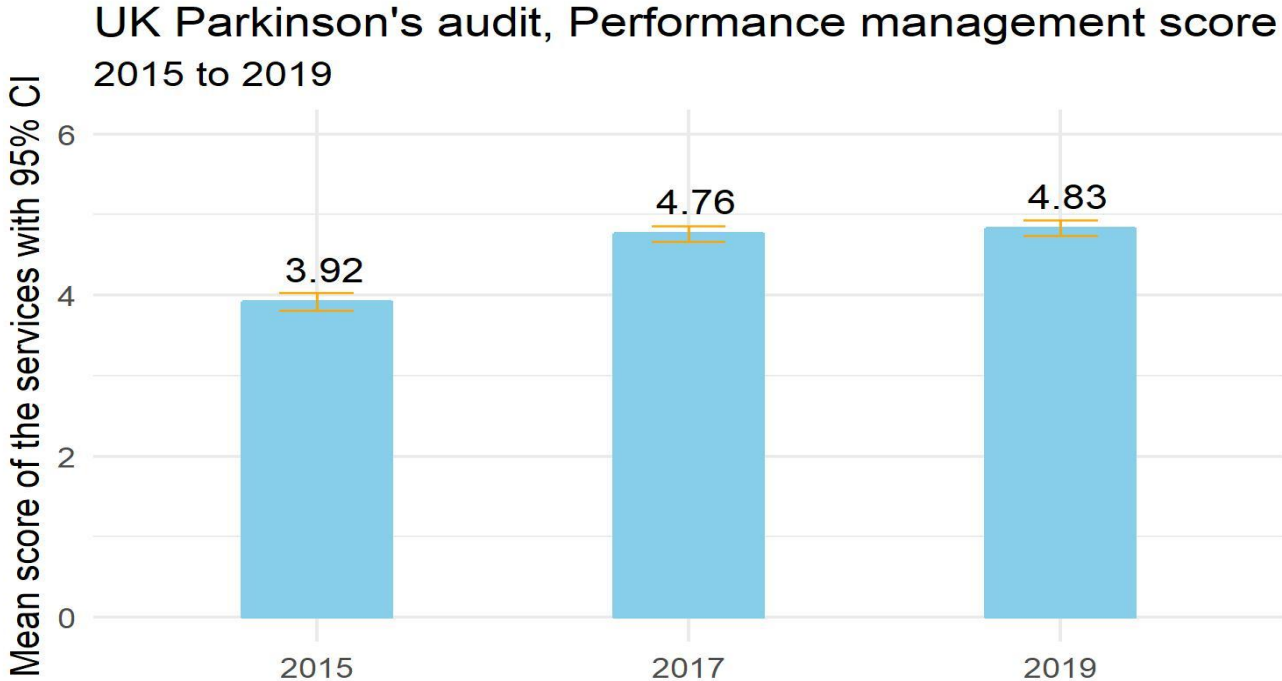
The number of responses to each of these were:

Year	YLYS	PREM
2015	3491	6526
2016	2829	
2017	2715	6446
2018	2912	
2019	690*	8247

\*For cost reasons, this was online only

# We will deliver a 25% improvement in the quality of Parkinson's services. **Partially met**

Improvement in quality was just shy of our 25% target at 23% (up from an average score of 3.92 in 2015 to 4.83 in 2019) - there was a significant improvement between the 2015 and 2017 audits with a smaller rise 2017 - 2019.

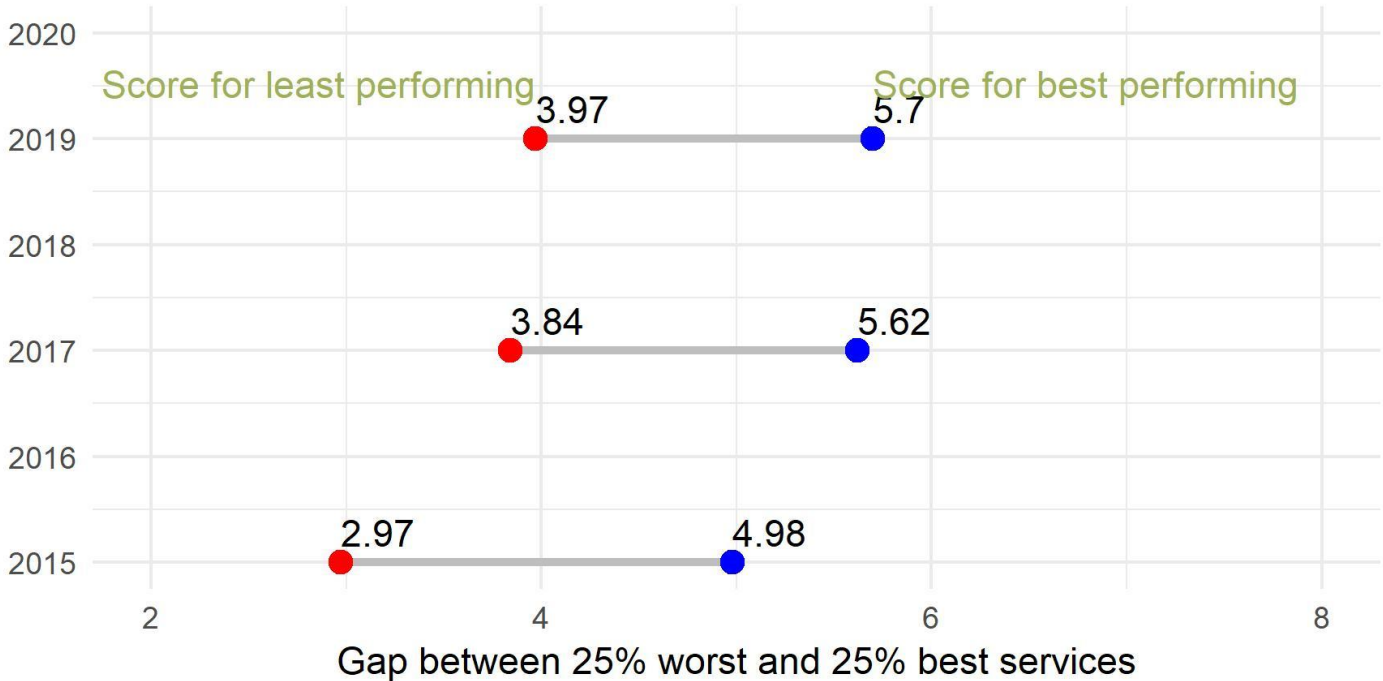


How this was calculated: Data used was 2015, 2017, 2019 PREM data. 7 questions from these datasets were selected (access to MDT team (4 questions), quality of consultant's service, feeling that a person is involved in decisions, feeling that the services are improving). These questions were recoded into 1 and 0 (1 - positive answer, 0 - negative answer). All 7 questions were summed to get a performance management score. The data was aggregated to the service level where each service got a score. These scores were averaged to give an overall score for all services which the chart shows.

# We will reduce the gap between the best and poorest quality services by 25%. **Partially met**

The gap between the best and worst services was only been reduced by c13% over the five year period. However the the average score for the 25% worst services has increased by 25%

Gap between worst and best performing services  
UK Parkinson's audit, 2015 to 2019



# 90% of people will be able to see a Parkinson's nurse, and 70% of people will be able to see specialist therapists.

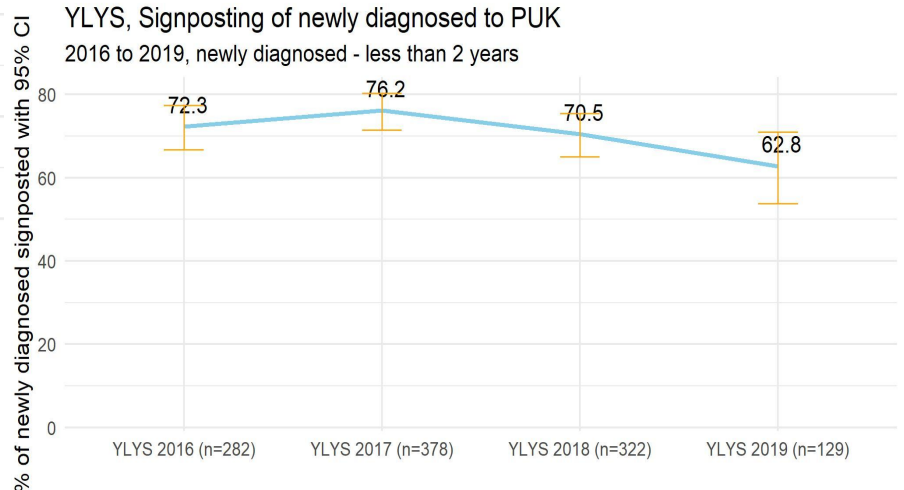
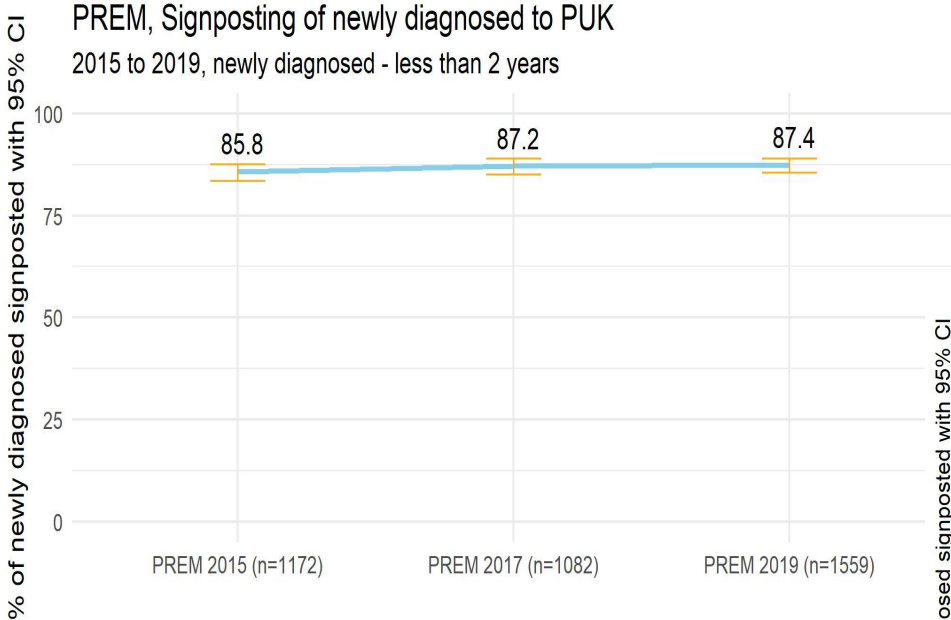
## Partially met

We fell short of our targets in this area. Access to a Parkinson's nurse was mostly consistent across the strategy period, but other specialist therapists became less accessible. This continues to be an area of focus for the [2020-24 strategy](#).

Specialist	2019 PREM	2019 YLYS
Parkinson's Nurse	89%	88%
Occupational Therapist	54%	30%
Physiotherapist	66%	48%
Speech & Language Therapist	48%	34%

# 80% of people will be signposted to Parkinson's UK when they are diagnosed. Fully met

There is a discrepancy between the PREM data in this area and the Your Life Your Services data that shows a different picture. PREM data is collected through services so it's not unexpected that this is tracking higher, and this is a more robust measure. Our shift towards a referral model rather than signposting in the new strategy will allow us more certainty in this area.



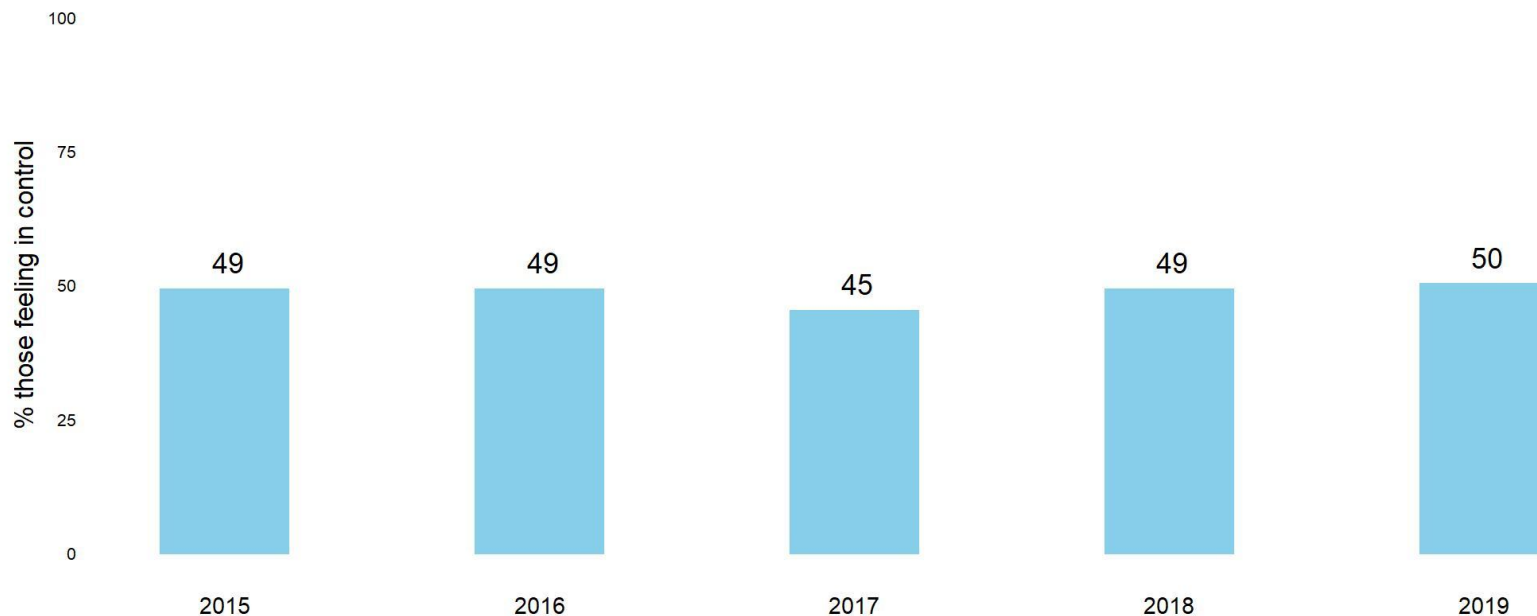
# Empowerment to Take Control

# There will be a 12% increase in the sense of control among people with Parkinson's. **Not met**

This calculated through a composite of 15 questions in the Your Life Your Services survey. There has been no significant shift in this area. The Your Life Your Services questions ask people to comment on their overall quality of life, not on the quality of the interventions that the charity has made, and the difference those interventions have made to people's quality of life. Other factors/changes in respondents' lives may reflect in their responses.

## YLYS, Feeling of being in control of the condition (%)

Taking control scale

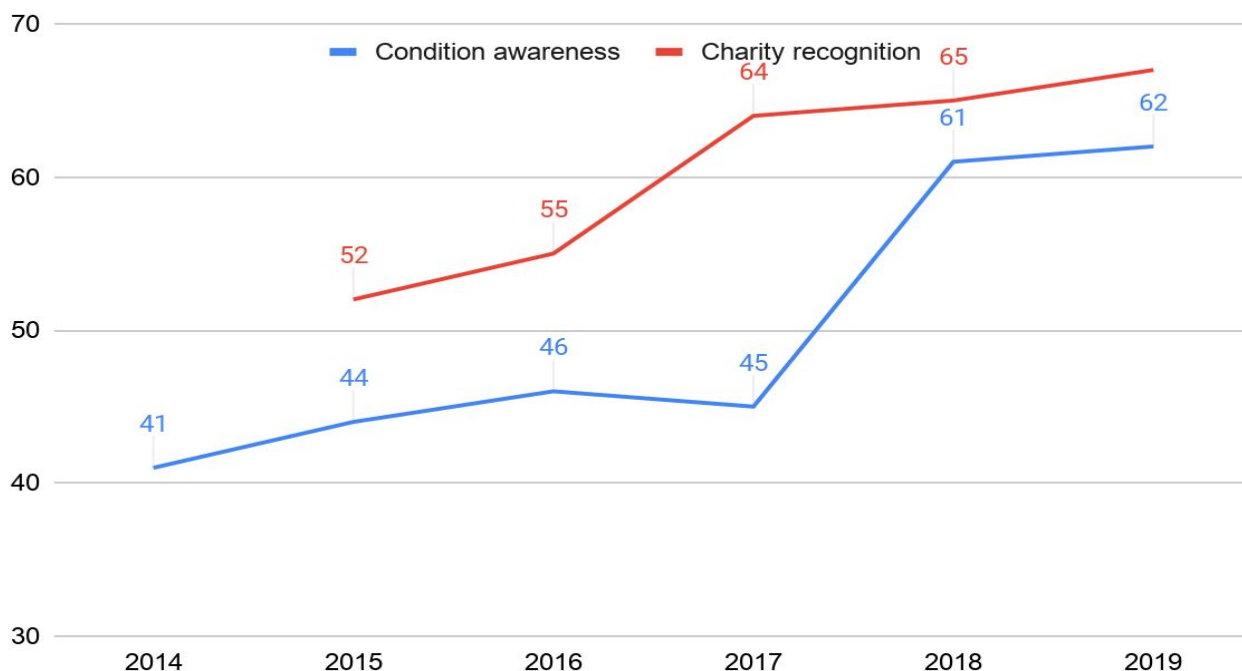




## 50% of the public will recognise Parkinson's as a serious health issue, and will have heard of Parkinson's UK. Fully met

We changed measurement provider during the strategy period to access more reliable insight, and adjusted the baseline to reflect this - this adjusted the initial strategy target from 50% to 62%.

In Q4 2019 there was a 62% prompted understanding of the condition and a 67% prompted awareness of the charity.



# Funding Our Activities

We will inspire people to raise £181m over 5 years, to fund our vital work improving care, treatments and quality of life.

Partially met

Year	Total Income
2015	£31.5m
2016	£32.7m
2017	£39.7m
2018	£35.2m
2019	£38.9m
Total	<b>£178m</b>

Points to note:

- We achieved 98% of our target.
- We achieved a 46% growth on the 2010-14 strategy (£122m).
- The 2019 figure excludes £8.3m of legacy income accrued into our accounts due to the change in recognition estimation technique.