

Nawr yw'r amser i siarad am roi organau
Time to talk about organ donation



Llywodraeth Cymru
Welsh Government

Human Transplantation (Wales) Act 2013

Report laid before the National Assembly for Wales
under Section 2.(3)

December 2017

Human Transplantation (Wales) Act 2013: Report laid before the National Assembly for Wales under Standing Order 2.3

Introduction

1. The Human Transplantation (Wales) Act 2013 (“the Act”) was given Royal Assent on 10 September 2013. The Act has created a system of consent to deceased organ donation in Wales. On 1 December 2015, Wales moved to a soft opt-out, or “deemed consent” system of consent to organ donation. This means that unless a person has stated otherwise, their consent to donation may be deemed to have been given and they will be treated as having no objection to becoming a donor. By making this change in the legislation and as it develops as “the norm”, Welsh Government expects to see an increase in donation over a period of time.
2. Whilst the majority of the provisions in the Act did not come into force until 1 December 2015, certain sections commenced on Royal Assent, most notably Section 2, which relates to Welsh Ministers’ duty to publicise the arrangements contained within the Act.
3. In addition, Section 2 (3) of the Act places an obligation on Welsh Ministers to report annually to the National Assembly for Wales for five years from September 2013 on work undertaken to:
 - Promote transplantation as a means of improving the health of people in Wales;
 - Provide information and increase awareness about transplantation;
 - Inform the public of the circumstances in which consent to transplantation activities is deemed to be given in the absence of express consent; and
 - Ensure that the resources available to local health boards include the specialist skills and competences required for the purpose of this Act.
4. This report is the fourth of five annual reports outlining the work undertaken to support this. The report covers the period of 15 November 2016 to 14 November 2017.

Background

5. The Human Transplantation (Wales) Act 2013 provides a framework for the introduction of a consent system to organ donation. This system is known as a “soft opt-out” or “deemed consent” system. The law provides a lever for a cultural shift in behaviour and attitudes towards increasing consent rates for organ donation.
6. In order for the system to be implemented smoothly and successfully, it was accompanied by a full public information campaign to ensure that the Welsh population were aware of the changes and understood how it affects them.

7. The primary role of the communications work between December 2013 and March 2016 was to: inform people of the legislative change; explain clearly the choices available to register an organ donation decision (express consent or express refusal) and the implications of not registering a decision, where an individual's consent may be deemed. However, the work was undertaken in the broad context of positive messages about organ donation and the difference it can make to the lives of individuals and their families. People were also being encouraged to talk to their loved ones about their decision.
8. From April 2016 the communications focused on reminding people of their choices and also encouraging them to talk to loved ones about their decision.
9. There was still some confusion among the public about the role of the family so in 2017, based on the latest evidence, we changed the focus of our communications work to encourage people to clarify their organ donation decision and to share it with those closest to them. This aims to address the issue of the family overriding a registered yes to donation on the organ donor register and not supporting deemed consent. It seeks to increase awareness of the role families/ partners have in honouring the decision of their loved ones, as well as encouraging people to share their decisions.

Objectives

10. The overriding policy objectives from the legislation are:

- Increase the number of organs available for transplantation;
- Create an environment where organ donation becomes the social norm.

11. Policy objectives for the current comms campaign:

- Reduce the number of families who override a registered yes on the organ donor register or who do not support deemed consent;
- Increase consent rates for organ donation;
- Increase donors and transplants;
- Increase the number of people who register a decision either on the organ donor register or by telling family and friends.

12. Communications objectives:

- To increase the number of people having a discussion with loved ones - this could be family, partners, or friends - about their organ donation decision (currently at 51%);
- To maintain understanding of the choices people have under deemed consent (currently at 73%).

Budget

13. The budget for all organ donation communications activity in 2017-18 increased to £350k to accommodate the advertising campaign (up from £200k in 2015-16).

Approach

14. The campaign began with PR activity in Organ Donation Week (4-10 September) followed by a multi-channel mass media campaign - supported by PR and social media - which launched on 1 November 2017.

We have continued to use case studies as part of PR activity as they have been successful in terms of coverage and reach.

Key Messages

- It is important to discuss your organ donation decision with your family.
- Your family would always be involved in discussions about whether organ donation should go ahead. It's important they know your decision so they can honour it.
- You can register a decision at any time by calling 0300 123 23 23 or visiting www.organdonationwales.org or by telling your family and friends.

Call to Action

15. New campaign materials (TV and radio adverts) prompt viewers to search Organ Donation Wales.

The web address is www.organdonationwales.org and our social media channels are: Twitter @OrgDonationCYM and Facebook @OrganDonationWales

Key Achievements

Public Relations

16. PR work, including proactive social media, was running throughout 2016-17.

The messages aimed to maintain understanding of the organ donation choices in Wales; promote conversations among loved ones, and encourage people to register a decision. Proactive stories have consistently generated positive coverage across the national and local titles online, in print and on broadcast channels. It supports advertising activity by providing stories of people who have been impacted by organ donation and the transplantation process. The real life case studies feature under the '*Your Stories*' section on the website.

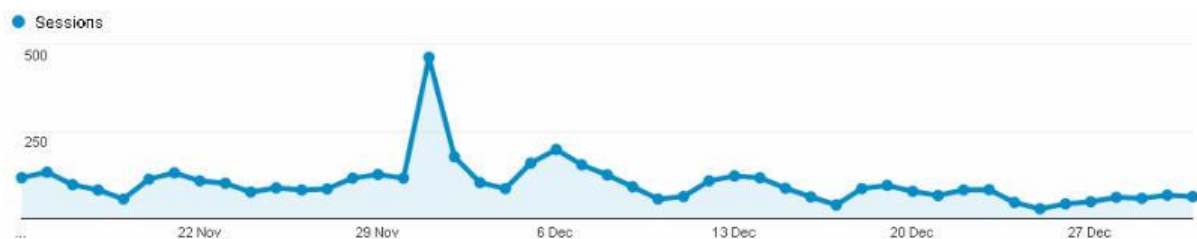
Website

17. Our campaign website continues to be our major call to action, providing lots of useful information about organ donation and the new system in Wales. The following graphs show the traffic to the website over the last year.

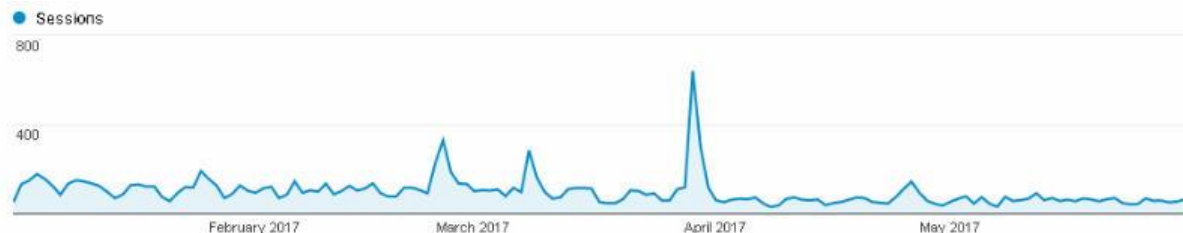
Since the launch of a dedicated website for organ donation in Wales, it has received over 352,898 visits, of which 84% are new visitors.

From 15 November 2016 until 14 November 2017 there were 40,376 visits and 85.5% new visitors.

November – December 2016



January – May 2017



June – November 2017



Information Materials

18. We updated the bilingual A5 information leaflet with a prompt to tell your family your decision. We have continued to promote and distribute a range of materials that were produced in alternative and accessible formats. This has included easy read, braille, large print, audio, British Sign Language video, as well as a range of ethnic minority languages.

Social media

19. Bilingual Facebook and Twitter channels support the campaign. Our approach has been to respond proactively to comments and questions where appropriate

to aid understanding of the system. The Facebook page has continued to be promoted through advertising. This has proved successful in terms of increasing reach. The page increased its 'likes' from over 4,000 (stats from 13/10/14) to 16,866 (14/11/2017). There was a correlation between advertising periods on Facebook and increases in 'likes'.

Our dedicated twitter channel now has 1,317 followers (correct at 14/11/2017).

Twitter: @OrgDonationCYM
Facebook: Organ Donation Wales

Stakeholder engagement

20. Stakeholder groups and partners were sent the campaign toolkit ahead of organ donation week. A range of stakeholders dialed in to a teleconference in September for a question-and-answer session about the new advertising campaign.

21. A stakeholder e-bulletin has been issued quarterly in 2016-17. The newsletter is published on www.wales.gov.uk/organdonation and is sent to approximately 370 people.

Organ Donation Week, 4 – 10 September 2017

22. Activity for organ donation week was PR-led and focused on conversations with family, using social media, face-to-face events and branded beer/ coffee coasters for the target audience of 18-34 year-old C2DE social groups and NEETs.

The coverage included:

Social media	<ul style="list-style-type: none">• Instagram - 5 bilingual branded stories with targeted promotional spend;• Snapchat - bilingual geo filter for Cardiff• University students;• Facebook/ Twitter - 24 bilingual posts and tweets in September with targeted promotional spend.
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Employer roadshows	<p>8 events across Wales at large employers, with high percentage of 18-34s in workforce. Roadshow stand and display banners, manned by SNOD (at three venues), and promotional crew. Campaign leaflets, pens, mugs, branded coasters issued to stand visitors and iPad used promote online registration.</p> <ul style="list-style-type: none"> • British Gas • DVLA • Go Compare • Admiral • BT • Carmarthenshire County Council • Powys County Council • MoneyPenny
Partnership with I Loves the 'Diff	<p>Custom joint branded ODW and ILtD bilingual beermats and posters using Taffywood books designs:</p> <ul style="list-style-type: none"> • 330 rugby clubs across Wales • 200 leisure outlets in South Wales.
Case Studies	<p>Video case studies with Mike Stephens, transplant surgeon; Eiddwen Glyn (Transplant Nurse); plus written case studies and photos of Jennifer Jones (Transplant recipient); Luke Morgan (Transplant recipient); and Gail Butterill (donor family).</p>
Press release	<p>National press notice with 2 case studies; 5 regional releases with case studies.</p>
Stakeholder toolkit	<p>Electronic toolkit of downloadable campaign resources issued out to 302 stakeholders.</p>

23. Reach

- 14.5m audience reached through OD Week bilingual media launch (pan Wales & UK).
- 16 mins national broadcast coverage.
- Over 24,000 employees had opportunity to see/hear (OTS/H) about campaign via employer roadshows.
- 150,000 18-34s per week in South East Wales had OTS/H about campaign via leisure outlet activity (posters & beermats).

- 150,000 18-34, C2DEs per week pan Wales had OTS/H about campaign via local rugby club activity (posters & beermats).
- Over 205,000 audience reach (targeted to 18-34s) via Instagram Stories (175,334 E & 30,083 W).
- 480 18-34s at Cardiff University had OTS Snapchat geo filter (direct & via friends sharing).
- Over 140,000 audience reach through Facebook and Twitter across September.

24. Engagement

- 23% open rate with 83 clicks on toolkit content (English version) & 19% with 5 clicks on toolkit content (Welsh version).
- 523 quality engagements at roadshow stand. 1,800 branded items given to employees. 15 OD registrations at stand.
- 2,686 direct clicks through to registration page on campaign website from Instagram Stories (2,263 E & 423 W).
- 41,480 engagements on Facebook (likes, comments, shares, video views).
- 2,181 engagements on Twitter (retweets, likes, video views).

25. Impact

- 5,486 new registrations in Wales in September 2017 (4,635 opt-in & 851 opt-out). This compares with 4,000 new registrations in August 2017 (3,519 opt-in & 481 opt-out).
- 31% uplift in campaign website sessions & 33% uplift in page views (for month of Sept '17 vs Aug '17).

26. Top performing posts during Organ Donation Week

Video short with transplant nurse (Eiddwen Glyn)

- 20,902 reach
- 7,052 engaged users (likes, comments, shares, video views).

Jennifer Jones case study GIF

- 9,881 reach
- 5,672 engaged users (likes, comments, shares, video views).

Pretty Vicious (Merthyr teen band) GIF

- 7,699 reach
- 3,600 engaged users (likes, comments & shares).

Video short with transplant surgeon (Mike Stephens)

- 8,369 reach

- 3,145 engaged users (likes, comments, shares, video views).

Luke Morgan case study GIF

- 4,734 reach
- 2,221 engaged users (likes, comments, shares, video views).


Examples of Organ Donation Week PR activity

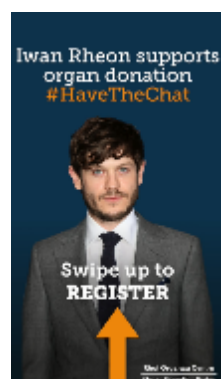




Mae Christian Amedeo, o 'I Loves The 'Diff', yn rhoddwr organau byw. Yn ddiweddar, fe roddodd ei un o'i arennau i'w wraig Helena. Cofrestrwch yma RhoiOrganau.org
Rhewch wybod i'ch teulu #CaelySgwrs

I ♥ S THE 'DIFF' **Rhoi Organau Cymru**
Organ Donation Wales

Christian Amedeo, of 'I Loves the 'Diff', is a living organ donor. He recently donated a kidney to his wife Helena.
Register at OrganDonationWales.org
Tell your family #HaveTheChat 



Advertising: launched 1 November 2017

27. The campaign is to address the issue of the family overriding a registered yes to donation on the organ donor register and not supporting deemed consent. It seeks to increase awareness of the role families/ partners have in honouring the decision of their loved ones, as well as encouraging people to share their decisions.

Evidence

28. Data published by NHS Blood and Transplant (NHSBT) for the financial year 2016-17, the first since the deemed consent system was introduced, shows:

- There were 21 cases where families have either overridden their relatives' decision on the organ donor register, or not supported deemed consent. With an average of 3.1 organs donated per donor this could have resulted in an additional 65 transplants.

- 61 deceased organ donors in Wales, which was 3 less than in the previous year.
- 187 organ transplants, compared to 214 in 2015-16.
- 235 people waiting for a transplant, this was an increase of 27 from 2015-16.
- 36 living donors, 6 more than in 2015-16.
- 22 people died whilst on the waiting list compared to 27 in 2015-16.

Social attitudes research

29. Questions about organ donation were asked in Wales Omnibus Surveys (run by Beaufort Research) from 2012 -2017. It is likely that the lack of support from family can be partly attributed to the fact the survey reports that the number of people who have discussed their decision with their loved ones has remained relatively low despite an increase from 38% in June 2012 to 51% in March 2017.

The new campaign will focus on the role of families on the process and the importance of having conversations with families/partners.

The Welsh Government will continue to undertake on-going research using the quarterly Wales Omnibus Survey to understand levels of awareness and reach of key messages.

30. Omnibus survey results from March 2017 showed that:

- 51% of respondents had discussed their wishes with loved ones. This increased from 48% in March 2016.
- 74% of respondents agreed that if an individual chooses not to register a decision, this should be treated as a decision to be a donor which families should be encouraged to accept. Down from 75% in March 2016.
- 73% of respondents were aware of changes to the organ donation system. Down from 82% in March 2016.

The latest reports are published here:

<http://gov.wales/statistics-and-research/public-attitudes-organ-donation/?lang=en>

31. In regards to age profiles, Omnibus data from June 2016 shows that 18-34 year olds are the least likely group to have discussed their organ donation decision with a family member (44% - June 2016).

While rates were higher in 35-54 year olds (55%), this age group will contain family members/parents who need to know and honour family members' decisions.

Full information in the report:

<http://gov.wales/docs/caecd/research/2016/160905-survey-public-attitudes-organ-donation-waves-10-11-12-en.pdf>

32. The new campaign encourages people to “**talk about organ donation, or someone else may speak for you**”.

Type of advertising	Specific channels
TV – running from 1 Nov to 17 Dec 2017	ITV S4C 4oD Sky Digital ITV Hub
Commercial radio	Heart South Wales Heart North Wales The Wave Radio Ceredigion
Online	In-read digital ads Facebook Twitter Instagram Google search ads

Media coverage of launch (1 November)

Date	Activity	Coverage
01/11/17	Half page feature on web news page with Specialist Nurse - Organ Donation (SNOD) interview	BBC.co.uk/Wales
	News story and interview with surgeon Mike Stephens (5 minutes long)	BBC Radio Wales Good Evening Wales
	News story and interview with Chief Medical Officer Frank Atherton, and case studies Joanna Duckworth and Michelle Powell (3 minutes long)	BBC Wales Today
	News story and interview with Anna Louise Bates, showed full 30 second TV advert	ITV Wales
	News story about advert featuring case study with local SNOD	SW Argus Online
		SW Argus
		Daily Post Online
		Swansea Sound Online
		Deeside.com
02/11/17	News story about advert and campaign	South Wales Evening Post

Examples of advertising

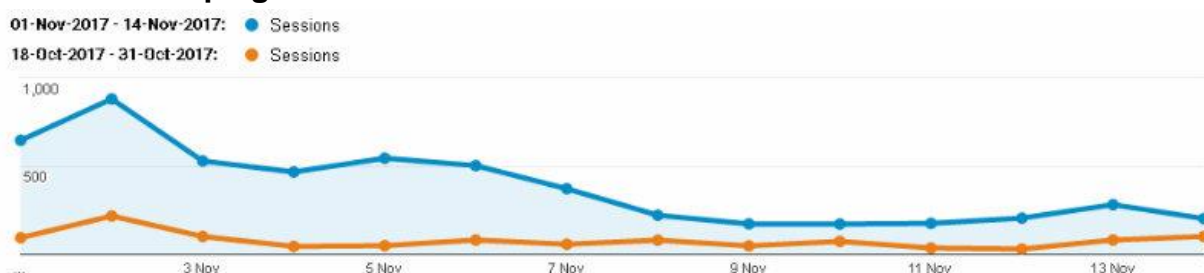
32. The TV adverts can be found on our Facebook or Twitter pages, or the video is hosted on Youtube:

<https://www.youtube.com/watch?v=iXPknPeUQM6>

Organ Donation Digital Update

33. Covering 1 – 14 November 2017 (weeks 1 - 2 of the family overrides campaign)

Traffic to campaign website



During the first 2 weeks of this campaign:

- Our campaign website received 5,376 sessions from 4,748 users. This was an increase of almost 400% when compared to the previous 2 weeks.
- 86.6% of people visiting the website were first time visitors compared to 82.5% in the previous 2 weeks.

We received **3684** clicks from our advertising this included:

- 2,155 clicks from Facebook advertising
- 1,015 clicks from Twitter advertising
- 291 clicks from Google search ads
- 162 clicks from In-read advertising (where our video appears within articles on other websites)
- 61 clicks from Instagram advertising.

Facebook

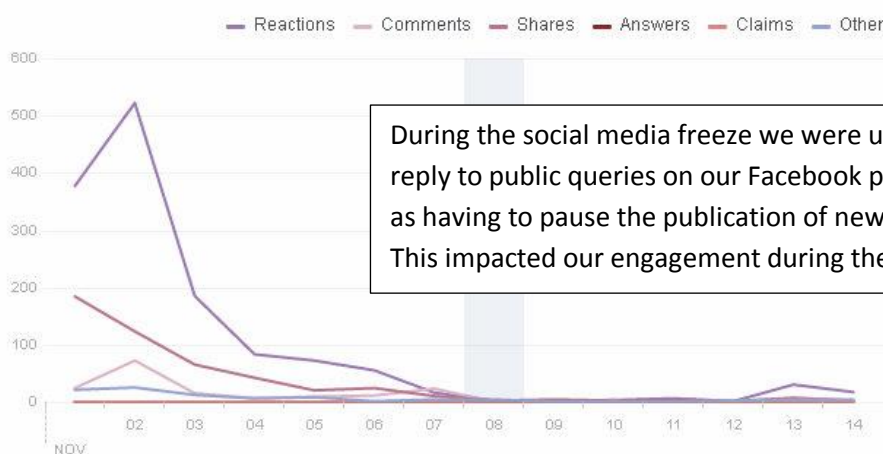
Total Reach

The number of people who were served any activity from your Page, including your posts, posts to your Page by other people, Page like adverts, mentions and check-ins.



Reactions, comments, shares and more

These actions will help you reach more people.



Twitter

During this time we achieved:

- 162,300 impressions; 1,800 link clicks; 193 retweets.



YouTube

We published our new TV advert on 1 November to both Facebook and the Welsh Government YouTube channel. The figures below cover the views on YouTube only.



English advert on Facebook:
13,300 views / 3,500 minutes viewed
English advert on YouTube:
818 views / 409 mins viewed

Welsh advert on Facebook:
1,300 views / 333 minutes viewed
Welsh advert on YouTube:
115 views / 60 mins viewed

Targeted communication activities

Students

34. We have continued an arrangement with UCAS to communicate directly with students who have accepted places in Welsh universities. This includes a direct e-mail and letter to their family home to ensure their family are aware.

The direct letter and e-mail were sent to almost 8,000 students from outside of Wales. The e-mail achieved a unique open rate of almost 58% with a click through rate of over 2%.

This work will be supported by PR work with universities and colleges to use their existing channels such as social media and newsletters.

16-18 year olds

35. A 'rising-18's' letter is being sent to everyone approaching their 18th birthday. It explains the new system, tell them what their choices are and encourages them to talk to their loved ones.

During the months of November 2016 and October 2017, over 36,000 letters were sent out.

Schools pack (key stage 3 & 4)

36. We have developed a bilingual education pack jointly with NHSBT for pupils aged 11-15. The pack which was delivered in September 2017 contains written and video case studies, lesson plans and resources. We are currently pilot testing this in a school. We will be adapting the pack in line with feedback received prior to a Wales-wide launch which is expected to be in early 2018.

Faith groups

37. We will continue to contact relevant groups to support the campaign and offer materials and/or content for their communication channels.

BAME communities

38. We will work to review and add to our existing contacts and resources to target these communities. Further work on engagement and targeted messaging is needed and a separate plan will be developed for year 2 of the new advertising campaign.

Skills and Competencies within the NHS

39. The Welsh Government has been working with NHS Blood and Transplant, the special health authority with responsibility for managing organ donation in Wales, to ensure that the operational management of the change in the consent system complies with the Human Tissue Authority Code of Practice on the Human Transplantation (Wales) Act 2013.

Specialist nurses in organ donation (SNOD) continue to undertake donation conversation training and work is ongoing to support the SNODs to manage the conversations. Activity in 2016-17 includes:

- Better communication between north and south Wales about consistency of auditing;
- Robust discussions about how best to audit complex scenarios;
- Shared practice meetings to discuss individual approach conversations and learn from experience;
- Additional work on communication, exploring opportunities with facilitators outside of the NHS.

Evaluation

40. Research and evaluation specifically for communications work includes regular public awareness and attitudes surveys.

Survey of Public Attitudes to Organ Donation: Wave 13 and 14

41. We have commissioned questions in the Wales Omnibus Survey to obtain regular information on public awareness and attitudes to changes in the organ donation system. Data are being collected at regular intervals between June 2012 and March 2020. Wave 13 (1,035 respondents) was conducted between 27 February and 12 March 2017 and wave 14 (1,008 respondents) was conducted between 18 September and 1 October 2017.

Key findings

- In wave 13, less than three quarters of respondents (73 per cent) reported that they were aware of any changes that had taken place to the organ donation system, decreasing to 70 per cent in wave 14. These figures show a decrease in unprompted awareness from a peak of 82 per cent in wave 11 (March 2016).
- After being shown a description of the new system, around eight out of ten respondents (81 per cent in wave 13; 79 per cent in wave 14) reported that they had seen or heard something about the change. These figures show a slight downward trend from a peak of 84 per cent in wave 11 (March 2016).
- Around half of respondents (51 per cent) in wave 13 said they had discussed their wishes with a family member, increasing to 55 per cent in wave 14. This figure remained at around four out of ten between wave 1 (June 2012) and wave 6 (June 2015) but has increased gradually since.
- Since the new soft opt-out system of organ donation was introduced:
 - almost two thirds of respondents (64 per cent in wave 13; 65 per cent in wave 14) had opted in or had done nothing as they were happy for deemed consent to apply;
 - one out of twenty respondents (5 per cent in waves 13 and 14) had opted out; and
 - three out of ten respondents (30 per cent in waves 13 and 14) said they were still considering their options; hadn't thought about it yet; or didn't know.
- Respondents who had registered to opt in, were happy for deemed consent to apply, or had opted out were asked: "Have you ever discussed that decision with a family member?" In waves 13 and 14 around two thirds of respondents (65 per cent wave 13; 67 per cent wave 14) had discussed their decision. These figures show a continued slight upward trend since the question was first asked in wave 11 (March 2016).

Forward Look and Priorities

42. A conference will take place on 1 December for health professionals and stakeholders to share organ donation and transplantation knowledge in Wales.
43. Impact assessment – published on 30 November 2017.
44. The communications budget for 2018-19 includes a second phase of the new campaign, pending evaluation of the current campaign, to begin in autumn 2018.
45. Updated BAME strategy and communications approach.