



The power of  
people's stories...

Care Opinion Scotland

**Annual Review**

April 2019 to March 2020

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## Chief Executive Summary – James Munro’s thoughts on 19/20




Care Opinion in Scotland has continued to grow, learn and develop during the year 2019-20, despite the challenges of Covid-19 towards the end of this period.

To begin at the end, the pandemic has of course posed significant challenges to all aspects of healthcare. Services across the NHS have worked overtime to change the way they are delivered to minimise risks to

patients and staff, and to address new needs. There has been a rapid shift to online and remote work, including clinical work. Paradoxically, in many services demand has fallen as patients have remained in lockdown.

Remarkably, in the midst of all of this Care Opinion’s online feedback service has continued with barely a missed beat. If anything, the changing nature of healthcare has led to new interest in online feedback and increased demands for new features, such as our new “campaign links” (perfectly suited for gathering feedback on remote consultations) and our “story slideshow” which enables feedback to be easily displayed in public spaces for patients and staff to see, without creating new infection control issues.

The year has seen continued international interest in Scotland’s leading role as an exemplar of system-wide online feedback (with all territorial boards now engaging with Care Opinion). In particular, we have shared Scotland’s experience with Western Canadian provinces and with a study tour of senior health service staff from South Africa. Closer to home, Scotland’s example has also informed and inspired health and social care leaders in Northern Ireland, where Care Opinion is expected to launch – again as a system-wide service – this summer.



**“Care Opinion’s  
online feedback  
service has  
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## Chief Executive Summary – James Munro’s thoughts on 19/20

Feedback activity across health boards has continued to grow and is shown elsewhere in this report. At the same time, health and social care partnerships are beginning to explore the potential for an integrated feedback system to match the integration of services. And discussions are continuing on how primary care might benefit from online feedback.

Research into online feedback, in the UK and elsewhere, has continued to gather interest. In January 2020 the Health Service Research Unit at Aberdeen University published a paper on the “anonymity paradox” in online feedback, and continues to develop research in this area via a funded PhD studentship. We would welcome further research partnerships with Scottish academic research teams, since online feedback remains new and unfamiliar to many staff and a range of uses and impacts are still to be explored.

There has also been change within the Care Opinion Scotland team. In March we said a tearful farewell to Gina Alexander, who over the past 9 years has made an extraordinary contribution as the first director of Care Opinion Scotland. In April we were delighted to welcome Fraser Gilmore as the new head of Care Opinion Scotland. Fraser has fitted right in, despite the constraints of the moment, and is already making a great impact. Earlier, in November, we also welcomed Dayle Goldie and

Danielle McEwan who provide valuable support to our Scottish subscribers.

Looking to the year ahead, our energy and passion for this work is unaffected by a virus or anything else. We continue to commit to our mission of innovation in the public interest, making feedback safer and simpler for everyone using health and social care services, and ensuring that people’s stories are heard and lead to widespread and visible learning and change.



**“We are delighted to welcome Fraser Gilmore as our new Head of Scotland..”**

Article photograph:- Right to left - Jason Leitch, National Clinical Director Scotland, Gina Alexander, James Munro & Derek Feely, IHI Director

## What you do makes a difference – Fraser Gilmore

Last year (2019/20) 4267 people across Scotland shared their experiences of health services on Care Opinion. This represented an almost 10% increase in stories from the previous year and an increase of almost 140% in the past 5 years.

As the newest member of the team at Care Opinion, I have been struck by the power of people's stories, the courage of the people who write them, the learning we can garner from them and the positive impact they can have on our health services.

This quote from Jane Goodall I think is a really good way of framing the motivations of both the authors of the stories on Care Opinion and the services who the stories are about.



**What you do makes a difference, and you have to decide what kind of difference you want to make.**

**Jane Goodall**



For our Authors, when they share their experiences, good or bad, they want to know their story will make a difference, and the detail of their story tells us what that difference is. This could be to give credit where its due, to offer suggestions, to talk about what could be changed and how the experience made them feel.

For services, by reading, responding and being open to change, makes all the difference. By actively engaging with authors, listening to what they have to say and acting upon it, shows authors and everyone else who reads the stories, the importance these services place on engaging with those who access their service's. Care Opinion plays an important part in creating an open dialogue between people accessing services and the services themselves. Both have a vested interest in positive outcomes and Care Opinion offers an independent space for this dialogue to happen.

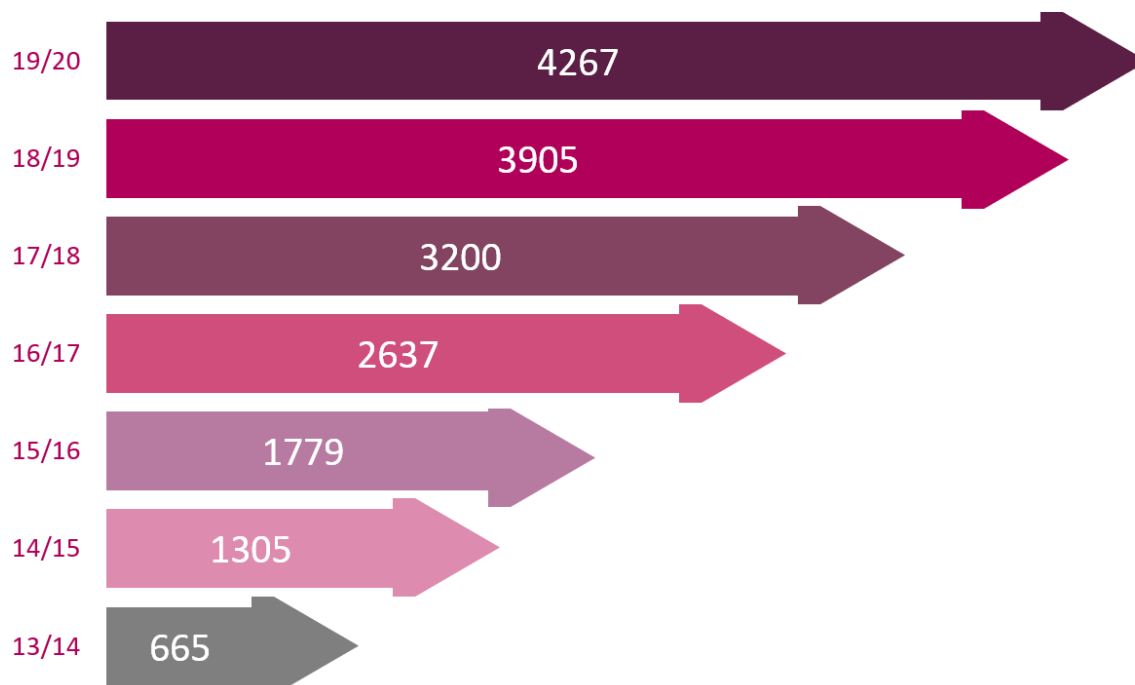
The increases we have seen in the numbers of stories show that Health Boards have been continuing to positively engage with Care Opinion and promote the service to patients and their families.

## Highlights

In 2019/20 in Scotland 4267 people shared their stories of health and care services on Care Opinion. Of these stories, 71% reported positive experiences with the remaining 29% giving critical feedback of the service they received. For both types of stories, 97% received a reply to their story. The stories in 2019/20 have already been read 649,166 times, averaging out at 152 per story.



Year on year, Care Opinion has seen increases in the number of people sharing their stories. Between 2018/19 and 2019/20 there was an almost 10% increase. In the past 5 years there has been an almost 140% increase and since 2013/14 there have been more than a 540% increase.



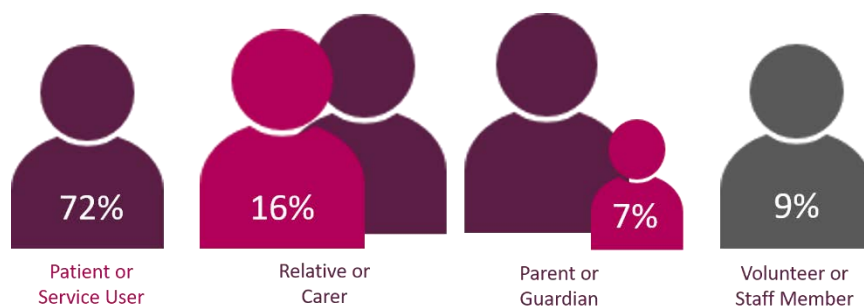
Year on year increases

## People behind the stories

### Who tells the stories on Care Opinion?

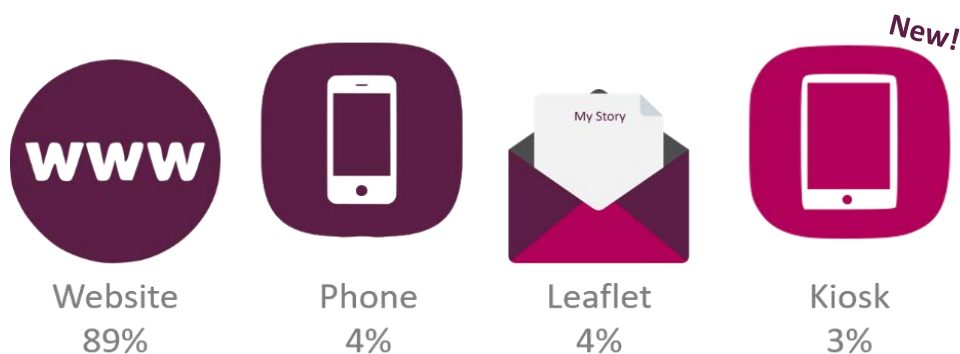
The journey of a story is very important. Who tells the story, what motivated them to tell the story and how they tell their story, tells us a lot about the background to the experience being shared.

In 2019/20 the majority of stories are shared by the patient or service users but many people share for a friend, relative or child. While volunteers make up a small proportion of people submitting stories on someone's behalf, this number is growing and we believe there is an opportunity to work with services and volunteers to a greater extent.



### What ways do people submit their story

In addition to understanding who tells their story on Care Opinion, we are also interested to see how people share their story. Most people primarily use the website but others chose a variety of ways to share...



## Kiosk mode - NHS Lanarkshire try out a new way to generate stories

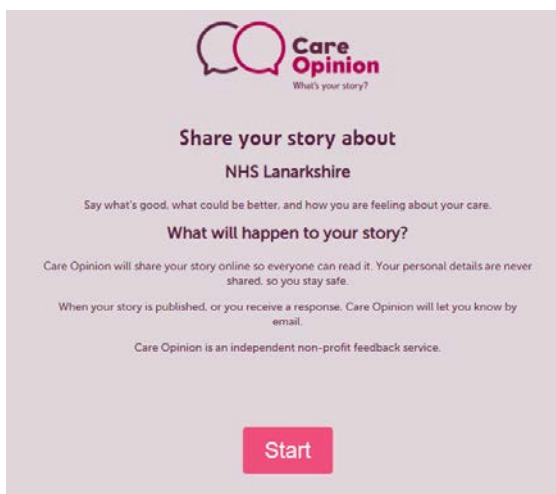
### What is Kiosk mode?

Kiosk mode is a new storytelling page which can be used for any service listed on Care Opinion. Any stories submitted through the kiosk mode page will automatically be linked to the single service for that page. The story form is more compact than our usual workflow and the story author isn't required to be logged in. Once a story is submitted, the page returns to the start ready for the next story.

All this makes kiosk mode a good solution when...

- you are collecting stories for one service,
- you might be sharing a device between people perhaps with a volunteer or using an iPad display,
- and you need a shorter, simpler storytelling workflow.

### Kiosk mode landing screen



The screenshot shows the Care Opinion kiosk mode landing screen for NHS Lanarkshire. At the top is the Care Opinion logo with the tagline 'What's your story?'. Below the logo, the text reads 'Share your story about NHS Lanarkshire'. Underneath, it says 'Say what's good, what could be better, and how you are feeling about your care.' The next section is titled 'What will happen to your story?' and contains two paragraphs: 'Care Opinion will share your story online so everyone can read it. Your personal details are never shared, so you stay safe.' and 'When your story is published, or you receive a response, Care Opinion will let you know by email.' At the bottom, it states 'Care Opinion is an independent non-profit feedback service.' and a prominent red 'Start' button is centered at the bottom.

When we moderate stories coming in through kiosk mode, we add the relevant tags and links to any additional services which are mentioned in the story, so we can join up care pathways.

As you can imagine, we were keen to see the impact of Kiosk mode on stories for NHS Lanarkshire

When we looked at the number of additional stories generated using Kiosk mode it was amazing to see that they had an additional **12%**, so an extra **110 stories!**

**Kiosk Mode = more stories + greater learning opportunities**



## Kiosk mode - NHS Lanarkshire try out a new way to generate stories

We followed up with NHS Lanarkshire to find out about their experience using Kiosk mode:

In what areas did you trial kiosk mode?

*"We have successfully used the kiosk in our 3 acute hospital sites in medical, surgical and care of the elderly wards. The Physiotherapy Department, Endoscopy Department and our Hospital at Home Team also use the kiosk to obtain patient feedback."*

Where has kiosk mode worked well and why?

*"The kiosk mode has worked well in all the areas we have used it. Our volunteers have found it particularly useful when speaking to inpatients at our 3 acute hospital sites as the fields are easy for them to populate, whilst chatting to the patients about their hospital experience. This has also been the case in the other 3 areas where the kiosk has been utilised from the feedback received from staff."*

Would you like to roll it out further? if so, where to?

*"It would be our intention to roll the use of the kiosk out further when we are able to recruit more volunteers for this function, however no decision has been made as yet as to where this will be."*

How do you promote the use of kiosk mode?

*"We promote the use of the kiosk mode when we are providing induction to staff responders and in conversation with staff. "*

What were your challenges in using kiosk mode?

*"The main challenges we initially encountered was network issues whilst working on site. To overcome the network issues if we get the error message on our iPads, we now take a screenshot of the story and populate the kiosk when we can connect to the network. Another challenge we had was populating the email addresses and postcodes. We found that sometimes the kiosk would not accept them. ... we now use an invalid.com email address and enter the postcode of the hospital site we are obtaining feedback for. "*



**110 more conversations about health and care services for NHS Lanarkshire**

**Imagine the possibilities across all health boards in Scotland**

## Stand out stories

As each year goes on there are the stories which catch our eyes, sad stories, uplifting stories, popular stories... This year a few have stood out for different reasons..

The most popular story this year..

" Day Case Hip Replacement "

STORY HAS A RESPONSE



This story has had 2 responses

“ Well I have read many negative comments in the press and on Facebook about the Victoria Hospital in Kirkcaldy but I can only say the care I got recently was excellent and exceeded my expectations by far... ”

" Compassionate, Caring Breast Care Nurse "

STORY HAS A RESPONSE



This story has had a response

“ At the end of last year, I found a lump in my breast which has required investigations and surgery at Raigmore hospital. Since discovering the lump and throughout treatment, I have been supported by Hazel, a Macmillan Breast Care Nurse at the Western Isles Hospital.... ”

## Staying active

Having more members on a subscription can increase sharing and learning from the stories received. It is good however to do a Care Opinion health check! This helps to ensure organisations are making the best use of their subscriptions.

Care Opinion has a function which allows organisations to look at their members registered to see who is actively reading and interacting with stories for their organisation

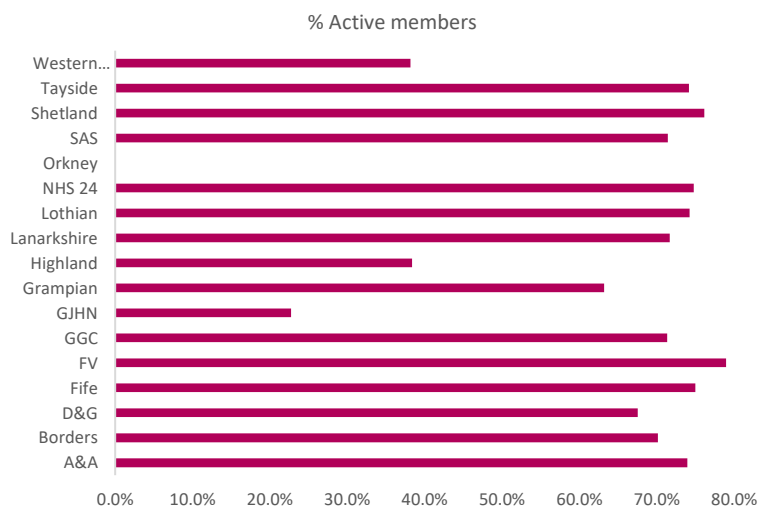


Subscription capacity is at **73%** across Scotland

There's room for **737** more members!

**70%** of registered members actively use CO

**11 boards in Scotland have over 70% of registered members actively using Care Opinion**



### Registered members



**60%** of registered members are responding to stories

## Macmillan partnership

This year we welcomed a [brand new partnership](#) with Macmillan Cancer Support in Scotland. The partnership signifies our shared commitment to the power of stories and how they can drive continuous improvement. Macmillan professionals across Scotland have received a pack of co-branded materials and an explanatory letter from Janice Malone, Engagement and Volunteering Manager.

This is the first step in a programme of awareness raising activities across the Macmillan community. We are looking forward to developing this partnership further and encouraging more stories together. This is of course only possible due to the commitment of all health boards in Scotland to the use of Care Opinion.



**How was your care?**

In partnership with  
**MACMILLAN  
CANCER SUPPORT**

**What's your story?**

At Care Opinion Scotland we are excited to be working in partnership with Macmillan Cancer Support Scotland

*"We believe that Care Opinion is a safe place where anyone can leave feedback about health and care services"*

Janice Malone, Engagement and Volunteering Manager  
Macmillan Cancer Support

Read more about our partnership here:-  
<http://tiny.cc/macmillanco>

Share your story at  
[careopinion.org.uk](http://careopinion.org.uk)  
or call  
**0800 122 31 35**

You can say...

- How you feel about the service you use?
- What's good about it?
- What's could have been better?

Care Opinion share your feedback with staff who run these services so they know what's good and what could be improved

Share your story about any health and social care services

Your story can improve care for everyone

We caught up recently with Janice to gather her thoughts on the ongoing partnership...

“ At Macmillan, the experience of people with cancer is vitally important to us. By understanding what matters to people, it allows us to learn and grow. It is our intention to develop support alongside people with cancer in ways that makes a difference to them. Our partnership with Care Opinion may only be in its infancy, but already we have seen that Macmillan Professionals in many setting across Scotland are interested in this work and we look forward to seeing how this progressive and innovative partnership continues to improve the lives of people with cancer. ”

## PhD Study – Emma Berry



Shortly before the lockdown Care Opinion welcomed Emma Berry to the team here in Stirling. Emma is working on her PhD which looks into how Care Opinion is used for quality improvement in NHS Scotland. Based at the University of Aberdeen, Emma started her PhD in Oct 2019 which will last for around 3 years. At the time of this report Emma was observing the team in Scotland (remotely due to Covid-19) and seeing how they do their work. She is fully immersed in meetings, and is training in the many aspects of the way we at Care Opinion achieve our aim.

At a later date Emma hopes to do some work with NHS staff and patients on their experience of Care Opinion. It is a pleasure to have Emma join us and we look forward to seeing her finalised work.



## Northern Ireland

In August 2020 Care Opinion will be launched as the new online user feedback system across all health and social care services in Northern Ireland.

Care Opinion has been working with the Public Health Agency, the Health and Social Care Trusts and



Ambulance Trust over the last few months to embed Care Opinion in services and raise awareness with staff. Several clinical teams have been running small scale pilots which have been well received by both service users and staff. From the beginning of August, Care Opinion will be promoted nationally as the place to go to leave public feedback about care.

The Care Opinion work in Northern Ireland is set in the context of the Bengoa Report (2016) which recommended there be “a platform for a more open and immediate conversation between staff and service users”. This was accepted by then Northern Ireland Health Minister Michelle O'Neill who in 2017 committed to “a new user feedback platform open to all those who both use and deliver our services”. Care Opinion was awarded the contract to provide this service for Northern Ireland. We are proud to be part of this system-wide approach to hearing the voices of patients, service users and carers.



Have a look at a recent [blog](#) from Linda Craig, the Regional Lead for Care Opinion

“ *Our work in Northern Ireland will be a true partnership, with plenty of learning in both directions. We are looking forward to continuing to improve and innovate our service to meet the demands of a new health system....*

*James Munro – Care Opinion* ”



## CO Australia rebrand



We asked our colleague Michael Greco, CEO of Care Opinion Australia what they have been up to and here is what he had to say:

“In Australia, like the UK, we started out in late 2011 as Patient Opinion for health services, and Care Opinion for social care. The Federal Health Minister at that time provided us with a soft launch at one of our

participating hospitals in Brisbane. Whilst it’s been a difficult journey at times (health services take time to see feedback as a social intervention where the focus is on ‘care’ and ‘conversation’, and not just an opportunity for gathering data), the rewards have been enormous both for our team and the subscribed health and social care services. We now have a whole State engaged for all their public hospitals (Western Australia) with some private hospitals involved too. Both Victoria and NSW are also undertaking pilots so we hope to have state-wide engagement in these areas. Having a whole country on board (like Scotland) has inspired us to think that we can engage all of Australian States and Territories in the next few years.



One of our significant changes recently has been the rebranding of Patient Opinion to Care Opinion. This step has strengthened our international identity and also been given the ‘thumbs up’ by most providers because it’s all about care, whether we are dealing with patients, clients, service users, etc. We are looking forward to the new brand, and walking alongside our subscribers in this journey of public online feedback focused on gratitude and improvement.”

## Looking forward – Care Opinion conference

### “The Power of online feedback in a post pandemic world”

In October this year, Care Opinion Scotland will be hosting an online conference on the theme of “The power of online feedback in a post pandemic world”.

At this one day event we will be bringing together the knowledge and experience of those working in the health and care sectors, academia, government, the third sector and some international friends, to help us explore our theme based on the Care Opinion model.

Our online conference will feature presentations, interactive sessions, Q&A’s and discussions on topics such as.

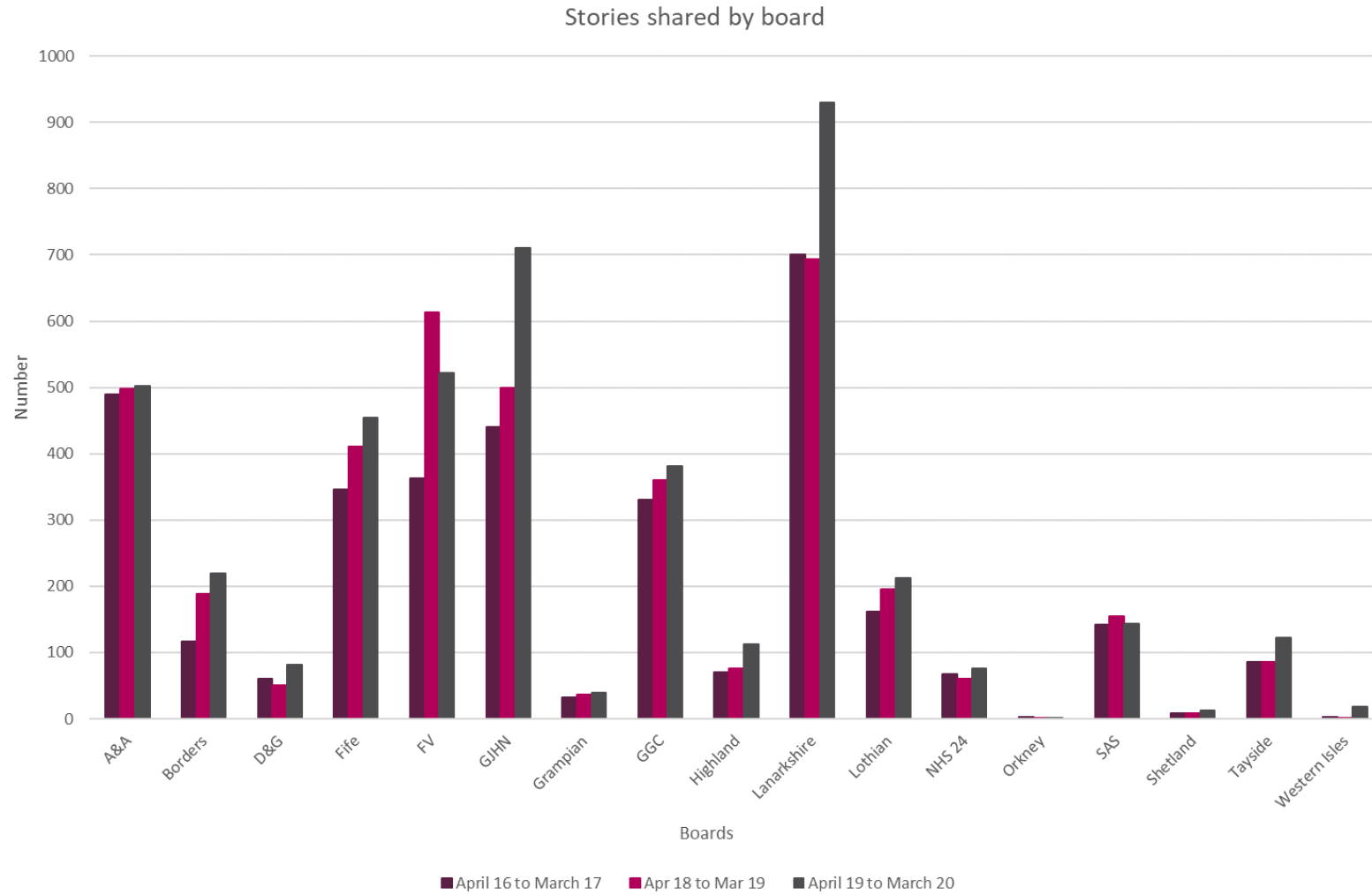
- The growing importance and uptake of online feedback in the current climate, over more traditional forms of engagement.
- Patient and service user engagement from an international perspective.
- How to encourage online feedback for health and care services.
- Using online feedback in the design and development of health and care services.
- How online feedback can and is being used in academia and the third sector to influence policy discussions.
- And much, much more...

So, if you are interested in the power of online communities where people can share their experiences of health and care services to help make them better for everyone, whether or not you are already a subscriber of Care Opinion’s, then this is the conference for you!

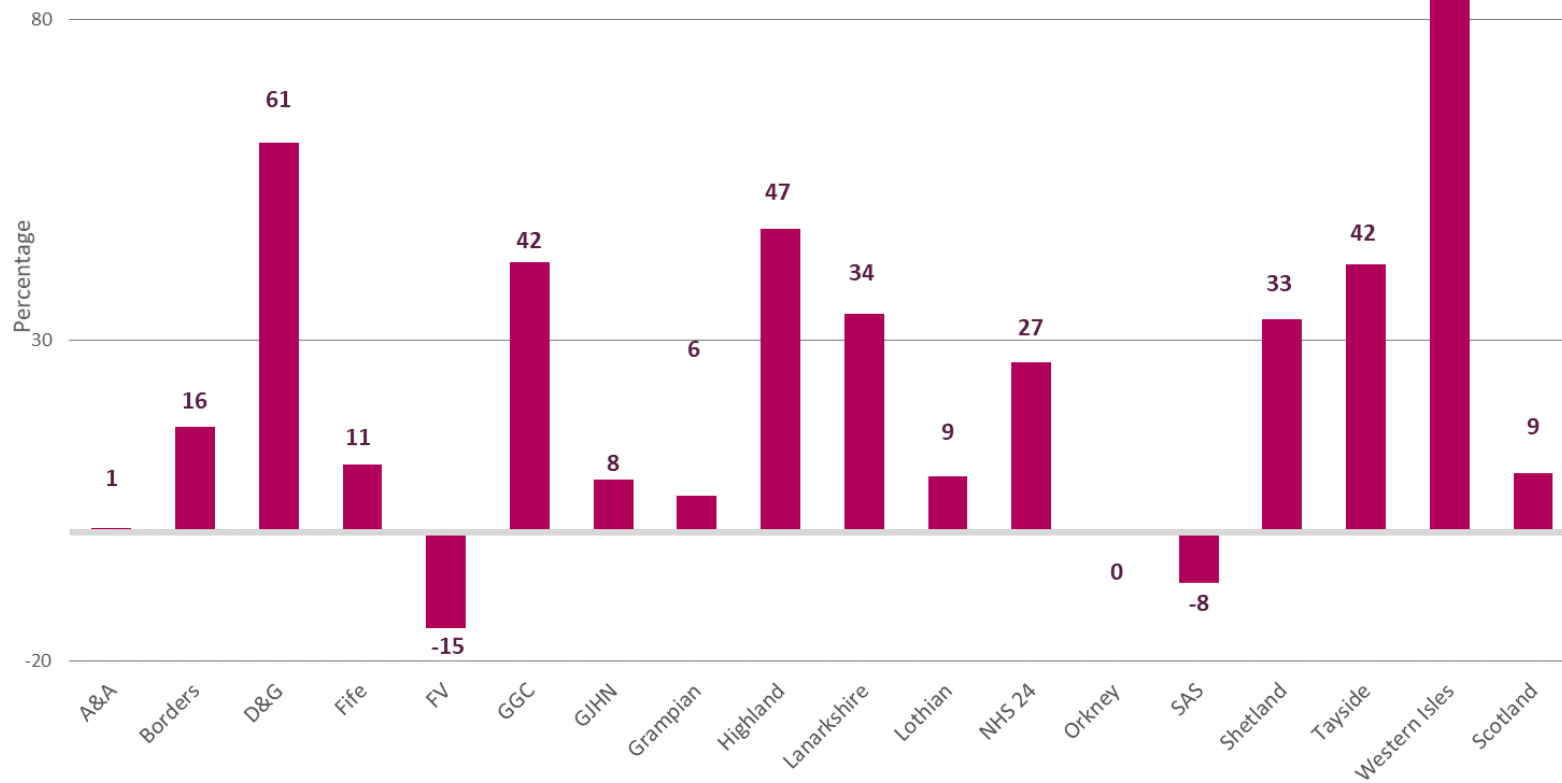


**We’ll be announcing the date very soon, so keep your eye on our website and social media for further information and look out for taster events that we will be hosting on the run up to the conference itself!**

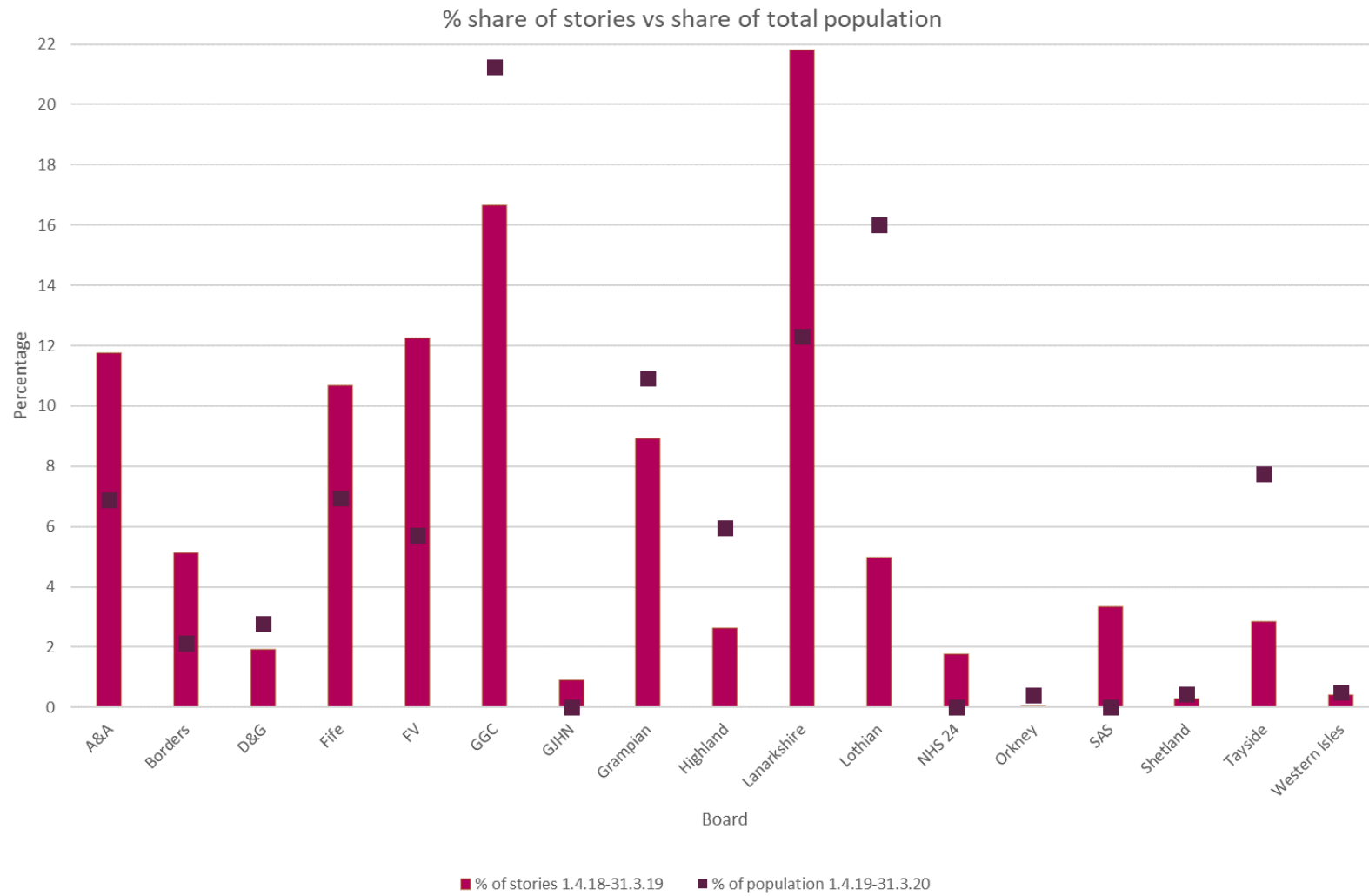




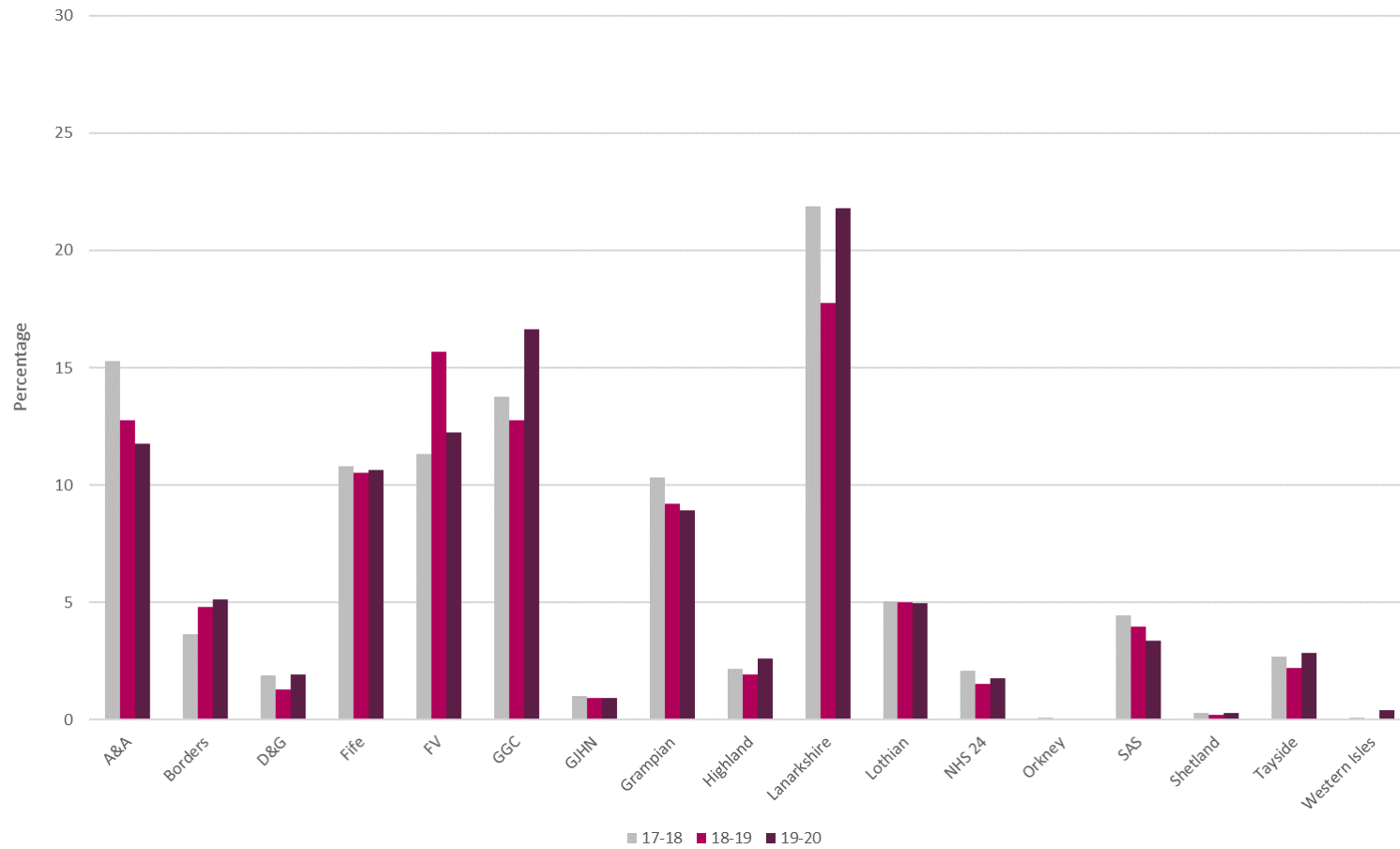
Increase /Decrease in Stories Shared



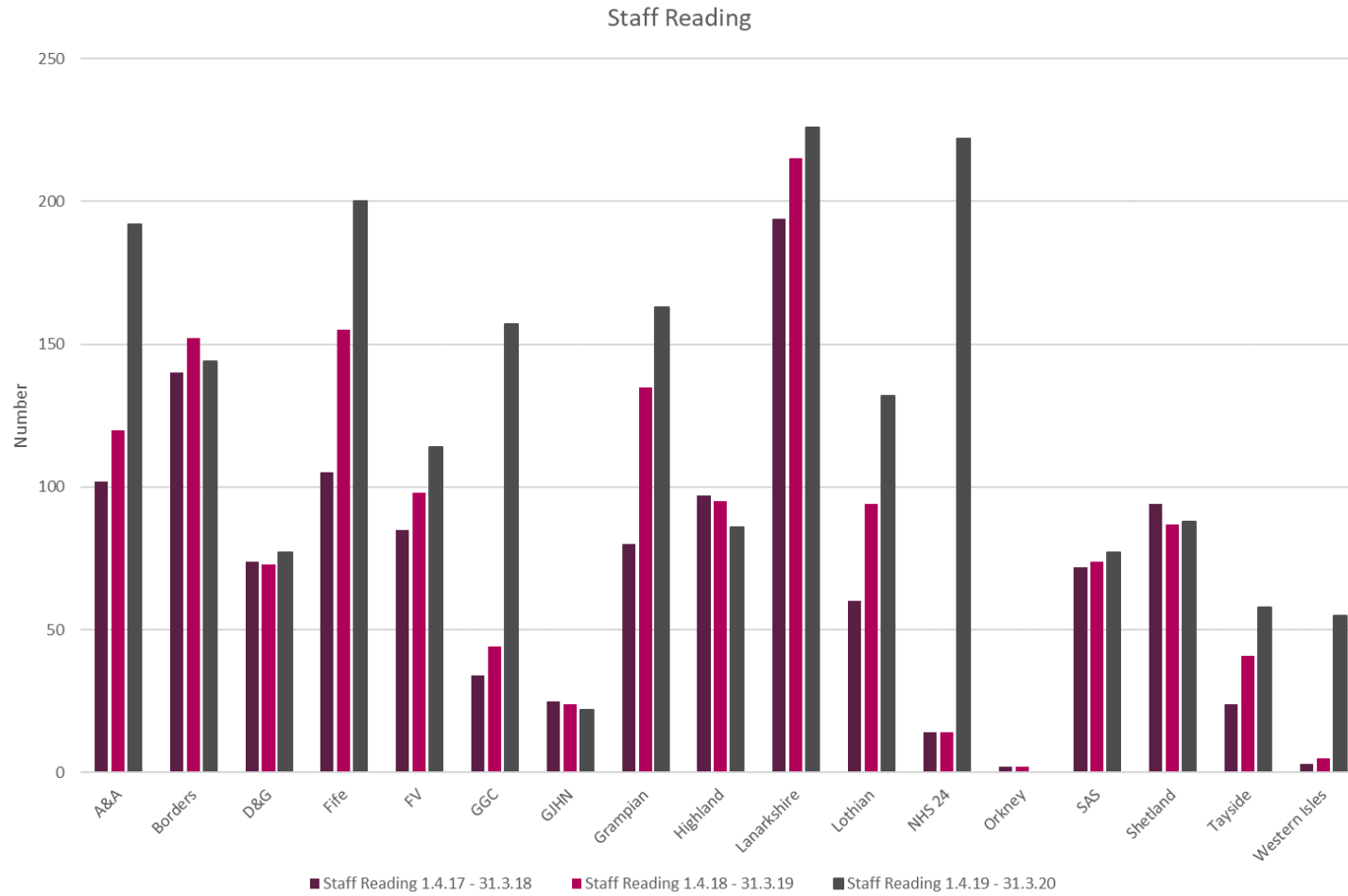
Increase/decrease in stories between Year 18/19 and Year 19/20



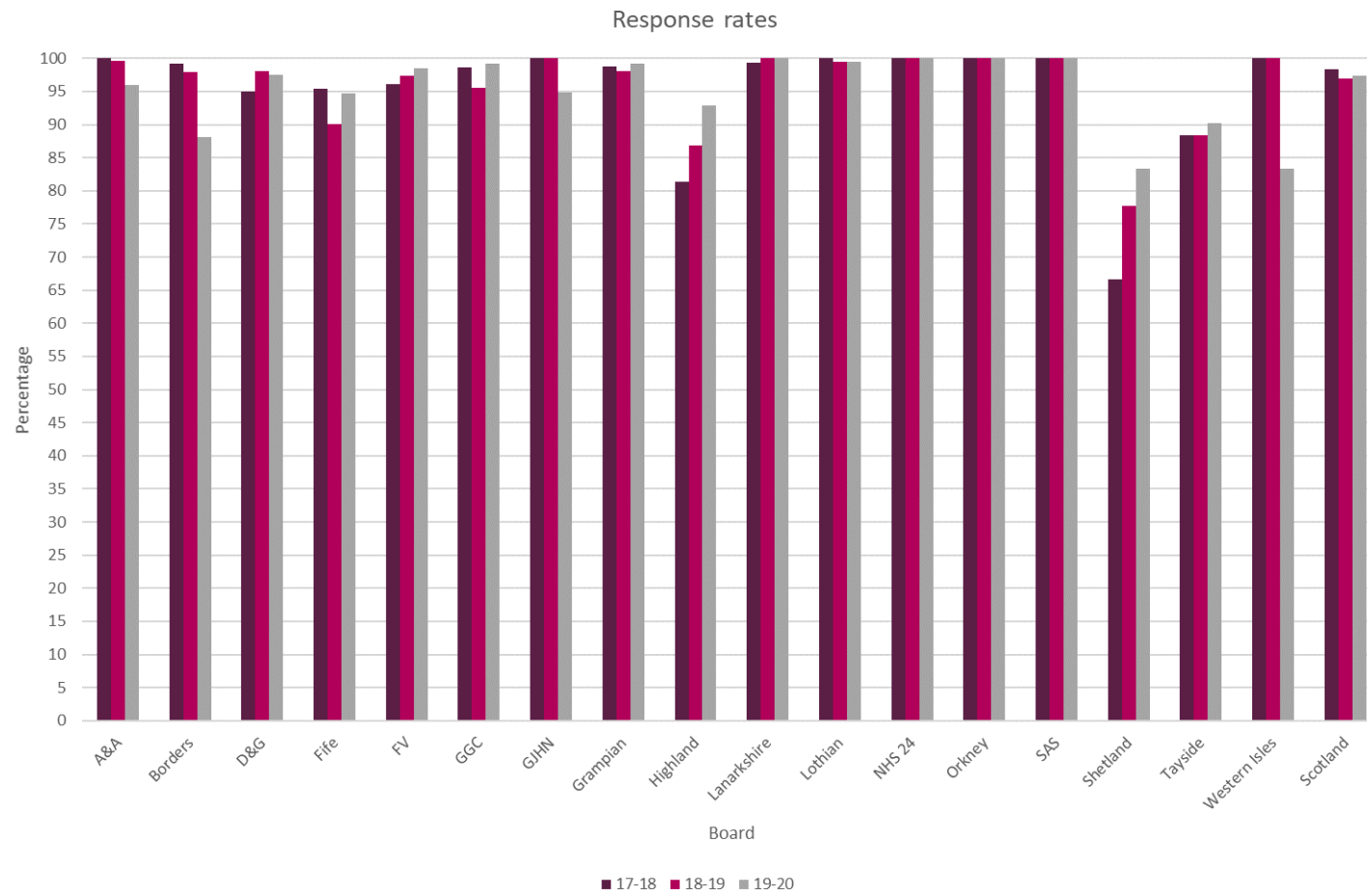
Stories as % of all Scottish stories



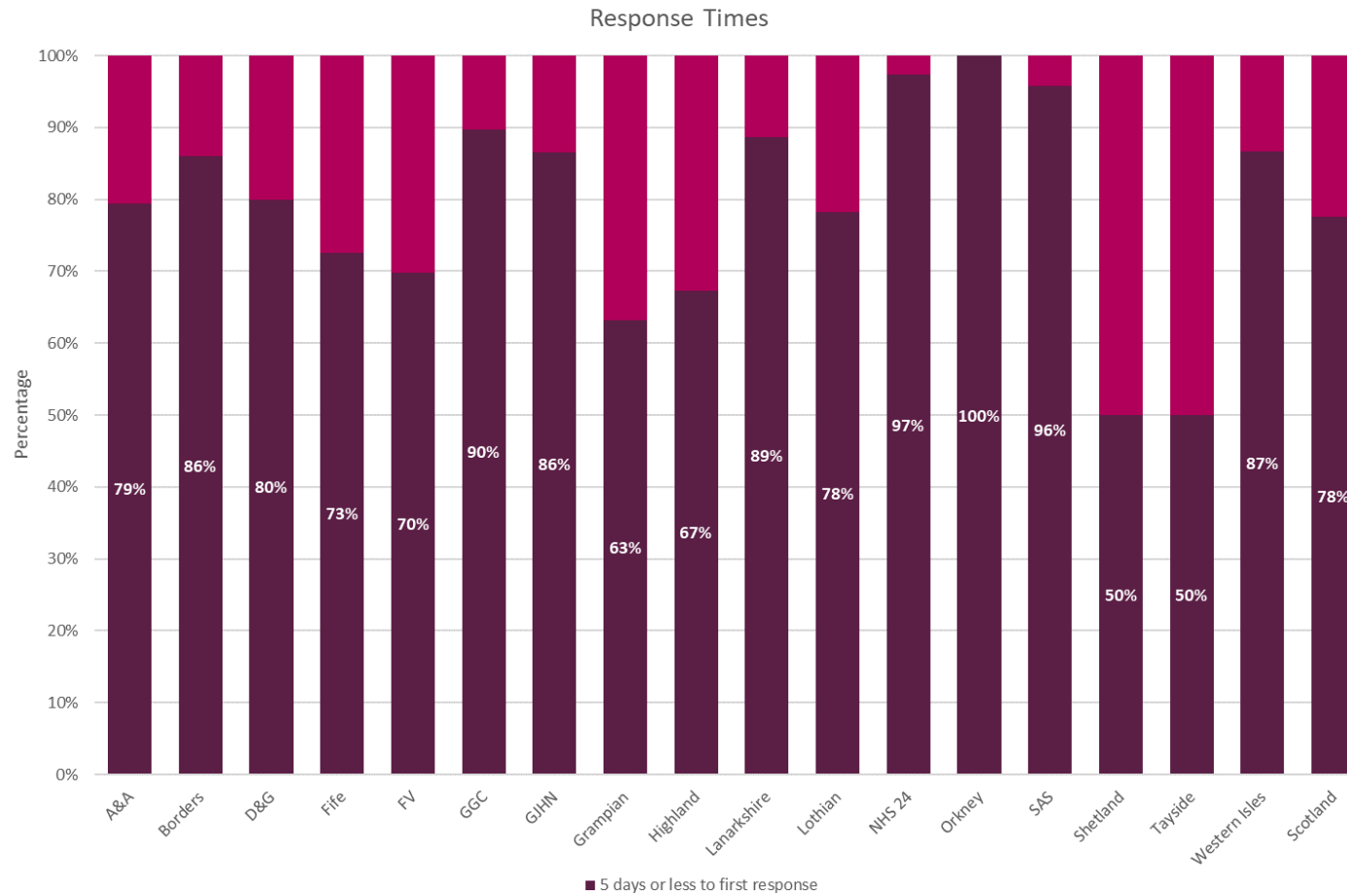
## Data & graphs



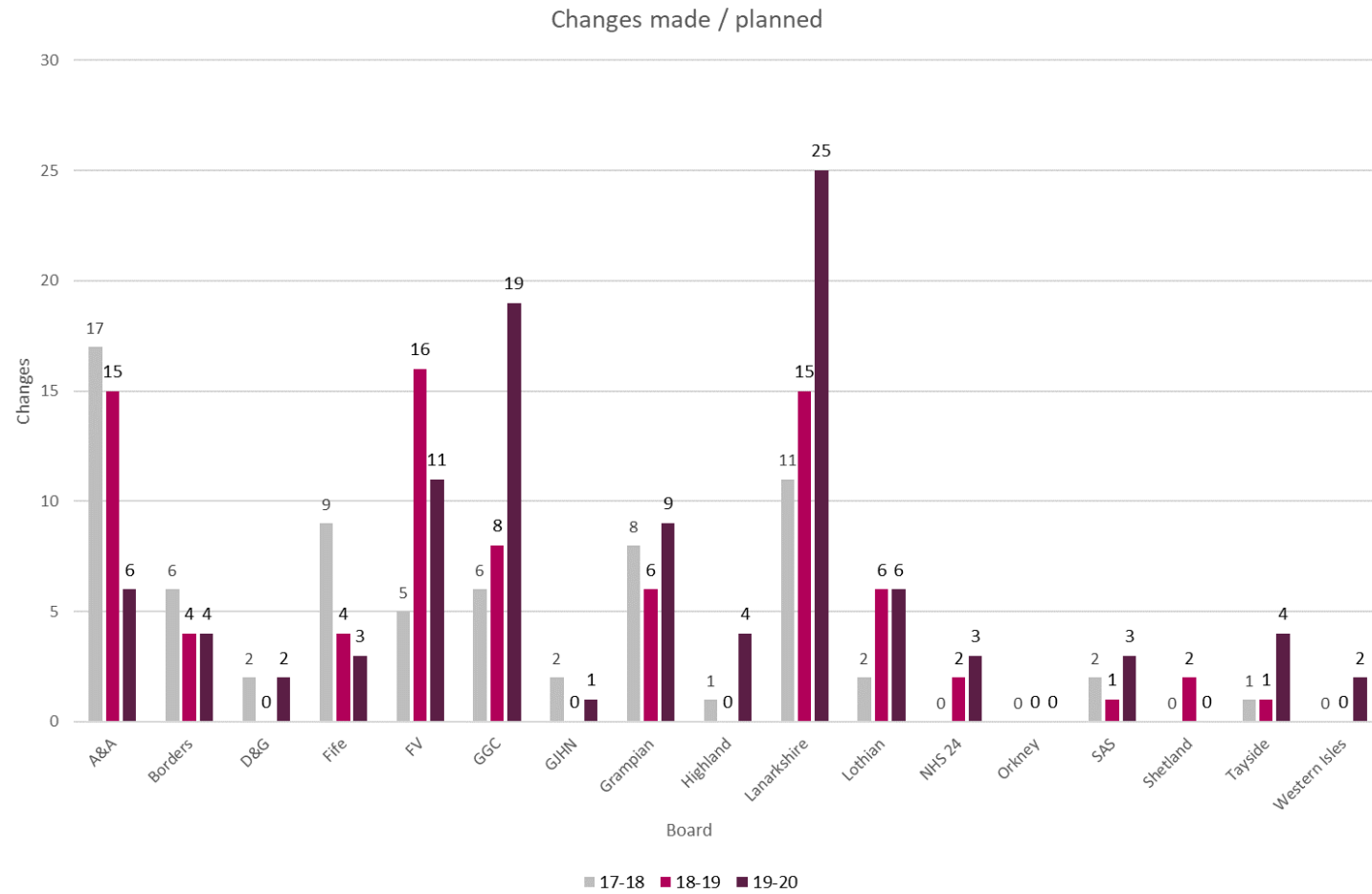
Data & graphs



## Data & graphs



Data & graphs





## Data & graphs

Data on all stories shared (1.4.19-31.3.20)

Board	Stories (n)	Response rate (%)	Stories responded to within 5 days	Responses (n)	% of critical stories which have led to change	Critical stories (n)	Changes (n)	% non critical stories	Reads (n)	Story read ratio	Staff reading
<b>A&amp;A</b>	502	96.0%	383	482	4%	137	6	73%	63,817	127	192
<b>Borders</b>	219	88.1%	166	193	11%	38	4	83%	24,720	113	144
<b>D&amp;G</b>	82	97.6%	64	80	5%	38	2	54%	8,931	109	77
<b>Fife</b>	455	94.7%	313	431	3%	97	3	79%	49,100	108	200
<b>FV</b>	522	98.5%	359	514	13%	85	11	84%	53,055	102	114
<b>GJHN</b>	39	1805.1%	632	704	5%	22	1	44%	5,636	162	157
<b>Grampian</b>	381	9.7%	32	37	9%	103	9	73%	143,366	145	22
<b>GGC</b>	710	53.2%	239	378	7%	258	19	64%	114,804	376	163
<b>Highland</b>	112	92.9%	70	104	21%	19	4	83%	11,942	107	86
<b>Lanarkshire</b>	930	100.0%	825	930	7%	335	25	64%	135,275	145	226
<b>Lothian</b>	212	99.5%	165	211	9%	69	6	67%	32,242	152	132
<b>NHS 24</b>	76	100.0%	74	76	11%	27	3	64%	17,306	228	222
<b>Orkney</b>	1	100.0%	1	1	0%	1	0	0%	101	101	0
<b>SAS</b>	143	100.0%	137	143	8%	36	3	75%	34,866	244	77
<b>Shetland</b>	12	83.3%	5	10	0%	7	0	42%	1,166	97	88
<b>Tayside</b>	122	90.2%	55	110	8%	48	4	61%	15,568	128	58
<b>Western Isles</b>	18	83.3%	13	15	0%	5	2	72%	3,377	188	55
<b>Scotland</b>	4267	97.3%	3221	4152	8%	1241	95	71%	649166	152	<b>2013</b>