

Assessing professional and public opinion of the HRA







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### Agenda



#### **Context**

#### **Key Findings:**

Public perceptions of health research

**Key Opinion Leaders** 

Chairs

Researchers

#### **Conclusions**





#### **CONTEXT**









## The HRA required an understanding of public & professional opinion about its work



**Objectives** 

Overall, to measure and understand views of the HRA and its work among members of the public and key stakeholders

This is an objective in the HRA's 2014/15 business plans and is a Key Performance Indicator for the HRA Board

The findings will be used to drive continual improvement within the HRA and to inform policy and communications

**Audiences** 

**General Public** 

**Key Opinion Leaders** 

Other stakeholders
Chairs/Vice Chairs
Researchers



#### Multiple audiences



#### **General Public**

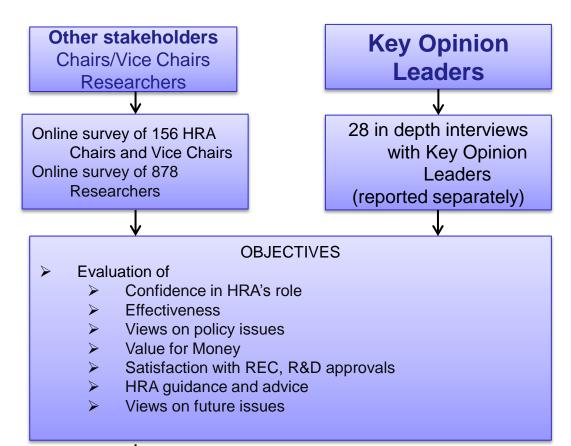
1,324 Face-to-face interviews with adults based in England (via omnibus)

Comparing the findings with a 2013 omnibus survey.

Setting benchmarks for future surveys.

#### **OBJECTIVES**

- >to measure public confidence in key roles for which the HRA is responsible
- ➤ to assess public attitudes towards participation in research
- > to assess public views on issues to inform comms



Research conducted from 12 November-4 December 2014
Response rates: 55% Chairs/Vice Chairs (91); 18% Researchers (156)
Weighting applied to Researchers' data to correct for oversampling non students
and reflect correct proportion: 41% students/59% non students









#### **KEY FINDINGS**

### **General Public**



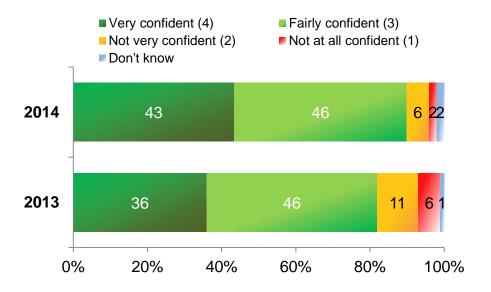


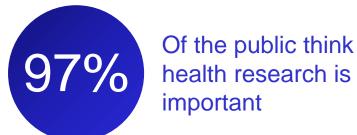
# The public's confidence that they would be treated with dignity and respect in a health research study has improved since last year

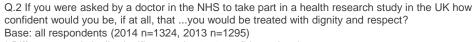


- Nearly nine out of ten members of the public (89%) say they feel very or fairly confident that they would be treated with dignity and respect if asked to take part in a health research study, up from 82% last year\*
- This overall increase is driven by the proportion feeling very confident, which has increased from 36% to 43%\*
- Confidence is lower among younger members of the public, those from a minority ethnic background and those in lower SEG groups
  - 36% of 25-34 year olds feel very confident that they would be treated with respect, compared to 51% of people aged 65+ \*
  - 31% of minority ethnic people feel very confident, compared to 45% of whites \*
  - 40% of DEs feel very confident they would be treated with respect, compared to 50% of ABs \*

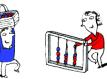
#### Confidence that would be treated with dignity and respect if asked to take part in a health research study









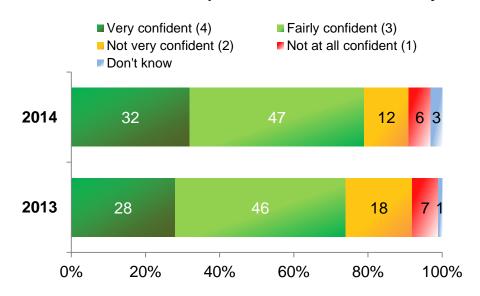


## The public feels more confident that their personal data would be held securely



- Nearly 8 out of 10 members of the public (79%) feel confident that their personal data would be held securely if they were asked to take part in a health research study
- This is an improvement since last year with the proportion of those feeling 'very confident' increasing from 28% to 32% this year \*
- Those in the highest social classes are more likely to feel confident, though the difference is less marked than last year
  - 35% of those in the AB groups feel very confident, compared to 30% of DEs
- Similarly, those from minority ethnic backgrounds continue to feel less confident in their data security than whites, but the difference is less strong than in 2013
  - 33% of whites feel very confident in their data security, compared to 27% of those from minority ethnic backgrounds

#### Confidence that personal data would be held securely if asked to take part in a health research study







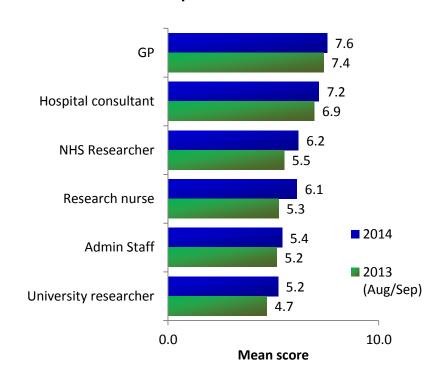
Q.3 If you were asked by a doctor in the NHS to take part in a health research study in the UK how confident would you be, if at all, that ...your personal data would be held securely? Base: all respondents (2014 n=1324, 2013 n=1295)

## The public continue to trust GPs and Hospital consultants the most to access their patient records



- GPs and hospital consultants continue to enjoy the most trust from the public when it comes to accessing their patient records
- In 2014, trust in both NHS researchers and research nurses has improved somewhat, with the public now happier with the idea of these groups accessing their records than admin staff or university researchers
- Although the mean scores show a similar pattern in 2013 and 2014, scores are less polarised in 2014 than 2013
  - For example in 2013 47% were very happy for their GP to see their records while 13% were not happy at all. In 2014 the comparable figures are 33% and 5%.

#### Views about the following people accessing your patient record?





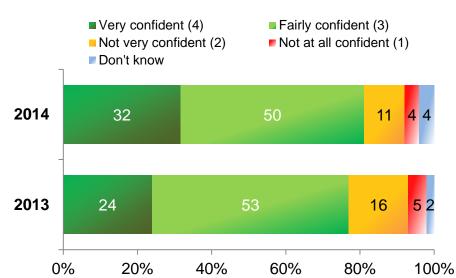


#### The public's confidence in research reviewed by an ethics committee has grown since last year



- The large majority 82% of the public feel confident about taking part in a health research study if it has been reviewed by an ethics committee
- This has improved since last year with the proportion of those feeling 'very confident' increasing from 24% in 2013 to 32% this year \*
- There is a marked difference in social grade, with those in the DE groups least likely to feel reassured by the involvement of an ethics committee
  - 42% of ABs and 35% of C1s feel 'very confident' if the study is reviewed by a Research Ethics committee, compared to 26% of C2s and 23% of DEs (\* AB vs C1 and C2 vs DE not significantly different, other differences significant)
- And, as observed last year, those from minority ethnic backgrounds are also less reassured by this
  - A third (34%) of whites feel very confident if an ethics committee is involved, compared to a fifth (21%) of those from minority ethnic backgrounds\*







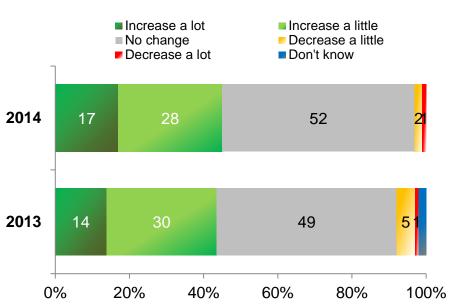


# Patient involvement continues to have a positive effect on public confidence in a research study



- The overall effect of patient involvement continues to be positive, with 45% of the public saying it would increase their confidence in a study and only a small proportion (3%) saying it would make them feel less confident
- This shows an improvement since last year when 6% said they would be less confident if patients were involved \*
- ABs are particularly likely to feel reassured by patient involvement, a pattern also seen last year
  - 26% of ABs say their confidence would 'increase a lot', compared to 15% of C1s, 15% of C2s and 14% of DEs (\*AB significantly different from other groups)
- But, those from minority ethnic backgrounds seem less sceptical than in 2013
  - Whereas in 2013, 14% of those from minority ethnic backgrounds said patient involvement would make them less confident, in 2014 only 4% said they felt this way – still higher than whites at 2%, but a substantial improvement\*

## Impact of patient and public involvement on confidence in the study







Q.5 Sometimes researchers work with groups of patients who have a particular condition to ensure that the information given to patients in a health research study is easily understandable and meaningful. If you were told that patients had been involved in this way, what impact would this have on your confidence in the study? Base: all respondents (2014 n=1324, 2013 n=1295)

<sup>:</sup> all respondents (2014 n=1324, 2013 n=1295)

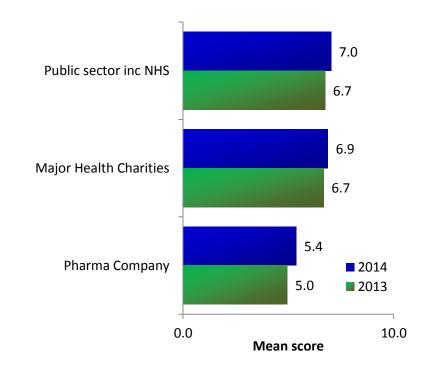
<sup>\*</sup> Difference statistically significant at the 95% confidence level

# Research funded by the pharmaceutical industry continues to be less trusted than that funded by the public sector or major charities



- Studies funded by the pharmaceutical industry are still less trusted than those funded by the public sector or major health charities, showing a similar pattern to last year
- The mean score on an 11-point scale of confidence in the research is 5.4 for studies run by pharmaceutical companies, compared to 7.0 for public sector studies and 6.9 for health charities (\*Difference between pharma and others statistically significant)
- And looking at those whose trust is highest, nearly one in five (19%) of the public say they are very confident in a study run by the public sector and a similar number (18%) feel very confident about a study run by a charity
- In contrast, less than one in 10 (8%) feel very confident in a study run by a pharmaceutical company\*

#### Confidence in taking part in a health research study funded by ...







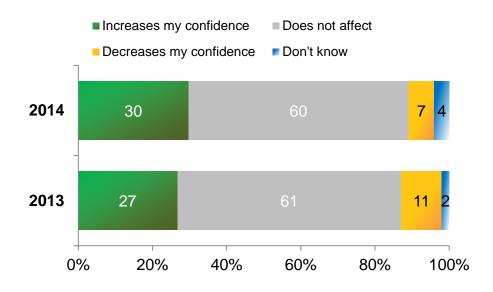
Q.6 To what extent would you feel confident or not about taking part in a health research study if you knew it was funded by ... ? (11 point scale 0=Not confident at all 10=Very confident)
Base: all respondents (2014 n=1324, 2013 n=1295)

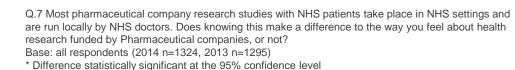
# Integration of pharmaceutical studies with the NHS has a largely neutral or positive impact on confidence in the study



- For most of the public (60%), the knowledge that most pharmaceutical studies take place in, and are run by, the NHS has no effect on their opinion of the study
- A slightly higher proportion than last year (30%) say it increases their confidence in the study, and the proportion who say it would decrease their confidence has declined
- The higher social groups are more positively influenced: ABs (32%) and C1s (34%) are more likely to say it increases their confidence than C2s (25%) and DEs (25%) (\* AB vs C1 and C2 vs DE not significantly different, other differences significant)

#### Impact on confidence of awareness of integration of pharmaceutical studies with NHS







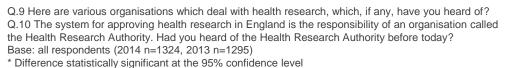


## Awareness of the HRA is relatively low among the public although it has increased slightly since 2013



- Around 1 in 5 members of the public (19%) claim to be aware of the HRA, up from 14% in 2013\*
- Claimed awareness of all the organisations has increased in 2014
- There is clearly some level of over-claim given the 14% who claim to be aware of the NPHF
- Claimed awareness is highest among ABs (26%) and lowest among C2s and DEs (15% in each case)\*
- 30% of the public claim to have heard of the HRA when prompted specifically about the organisation
- Again, there is a difference by socioeconomic group; ABs are most likely to claim they had heard of the HRA (38%) and DEs least likely (25%)\*





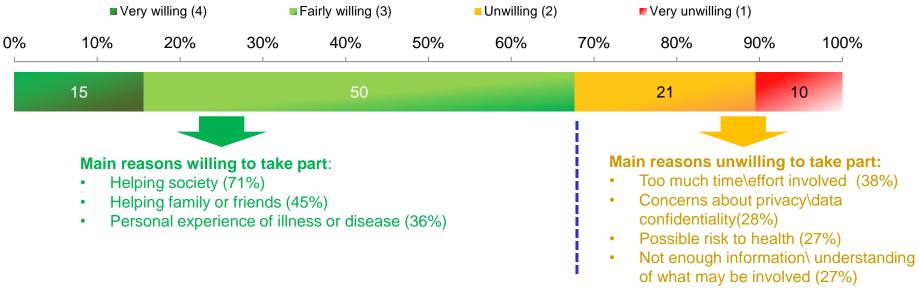




Many members of the public are willing to take part in health research, and many agree that everybody should be offered the opportunity to take part, but more communication could overcome barriers and improve participation



- Most members of the public (65%) say they would be willing to take part in health research, often citing altruistic reasons
- Willingness is higher in the upper socioeconomic groups, with three-quarters (76%) of ABs willing to take part compared to half (53%) of DEs\*
- There is potential to overcome unwillingness to take part through education to address the key concerns, particularly about privacy and data confidentiality, and generally providing more information about what would be involved
   Willingness to take part in health research



Q.12 If you were asked, how willing or unwilling would you be to take part in health and social care research? Base: all respondents (2014 n=1324)





Q.13 What would be your motivations for taking part in health and social care research? Base: all willing to take part n=810

Q.14 What would be your reasons for not taking part? Base: all not willing to take part n=505

<sup>\*</sup> Difference statistically significant at the 95% confidence level





#### **KEY FINDINGS**

### **Key Opinion Leaders**





#### The HRA's Key Opinion Leaders

- The HRA's Key Opinion Leaders include representatives from
  - Regulatory bodies
  - Academia
  - Industry
  - Government/public bodies
  - Charities
  - Medical
- There was a good level of awareness of the HRA and its agenda; many of the stakeholders had been involved with the HRA since its inception and for others, knowledge had grown over the 3 years of HRA's existence
  - There was a clear understanding of the HRA's purpose and role for most
- There was a reasonable level of confidence in the HRA's ability to deliver its strategic goals
  - They see strong leadership as driving this
  - Where there were areas of less confidence, this is often outside HRA's influence: the length of time it's been in existence, constraints placed on it by government policy
  - But could communicate its progress more confidently
- And it's felt to be doing a better job than a year ago



"I think they are very good at communicating with their stakeholders and it's one of the things that we've been particularly impressed with, that they send regular updates all the time, they have stakeholder meetings. I think they've made a real effort to make sure people understand what their aims are and what they're doing"

"I think it is about having a system by which we regulate clinical research which gets the balance right between fundamentally improving health and wellbeing for patients and the public and promoting that interest in a safe way, but enabling researchers and research institutions to do their job well, and with the least unnecessary interference possible; I think it is about balancing those two"

"Because of their early age, there's maybe not a huge list of evidence yet."





#### The HRA's Key Opinion Leaders

- Key achievements have been
  - Reducing approval times
  - Transparency
  - Taking a more strategic view
  - Improving the quality of ethics committees
  - Developing collaborative approach with other key opinion leaders
- Pace of change about right/too slow
  - They understand the reasons
  - But progress could be communicated better
- Key strengths
  - Its people and their understanding of the issues
  - Leadership
  - Efficiency
  - Helpful, 'can do' attitude
  - Collaboration with other bodies
- Weaknesses
  - Outweighed by strengths
  - Lack of/impact of communication



"I know that they have been successful in significantly reducing approval times for ethical approval and having more consistency around there"

> "I think their biggest achievement is probably the fact they've maintained their focus...they did a very, very good job of not allowing themselves to become the victim of mission drift"

"Credit goes particularly to their leadership, but also actually when I meet the other staff they're very approachable and they feel like deal makers, not deal breakers"

"They have a very collaborative approach, a very strong focus on addressing the bottlenecks which either prevent research happening or make it more bureaucratic or expensive and so on"

"Sometimes things change and I don't seem to be aware of it"





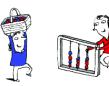
#### The HRA's Key Opinion Leaders

- Most feel a good balance has been struck between the needs of the organisation's differing stakeholders
- The involvement of the public is seen as critical
  - Transparency must be integral to the research process
  - Clear and easily understandable dialogue
- The HRA consults, seeks their views and listens
- But there is a need to be more proactive in its communications, with more frequent and 'punchy' updates highlighting its progress
- Virtually everyone was favourable towards the HRA.
   The main reasons for very favourable views were the ambitious agenda the HRA had embarked upon and its ability to consult, listen and respond to stakeholder concerns



"I have been quite impressed with the seriousness with which they've taken the public dialogue and the public engagement. I think the way they've managed to embrace a very complex remit of both supporting research but also protecting the public, I think they've done that in a very responsible way and the way they've brought public dialogue in from the beginning I think is another success".

"The impression that HRA leadership have given has been that they very much have at heart the streamlining of regulation and governance.... And I see them making progress and I actually, more importantly, I see them making progress and taking people with them".







#### **KEY FINDINGS**

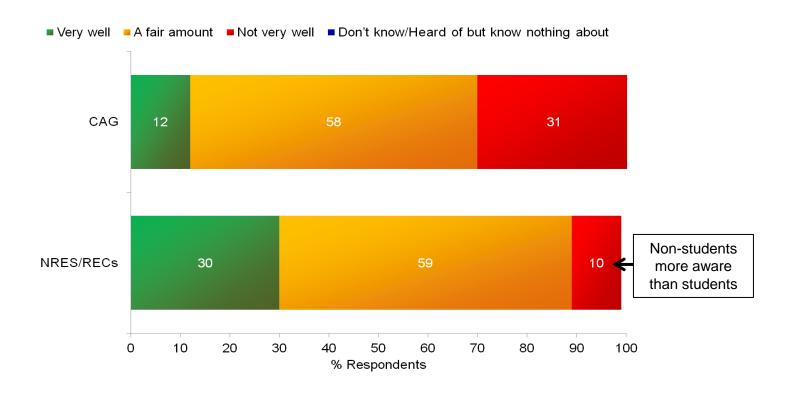
### Researchers





### Researchers are well-informed about NRES/RECs, much less so about the CAG





Awareness of HRA tools is high:

"Is it research?" 70%

"Do I need NHS REC approval?" 78%

CAG's pre-application advice 78%

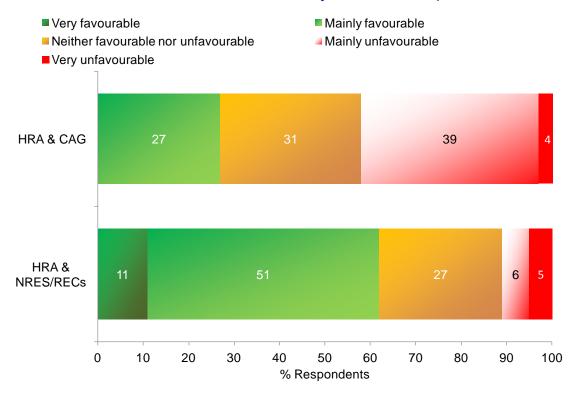




## Favourable overall opinion of HRA and its NRES



6 in 10 Researchers are favourable to HRA and NRES (especially non students and those very familiar with RECs) while Researchers have more mixed views of CAG (4 in 10 unfavourable, none very favourable)



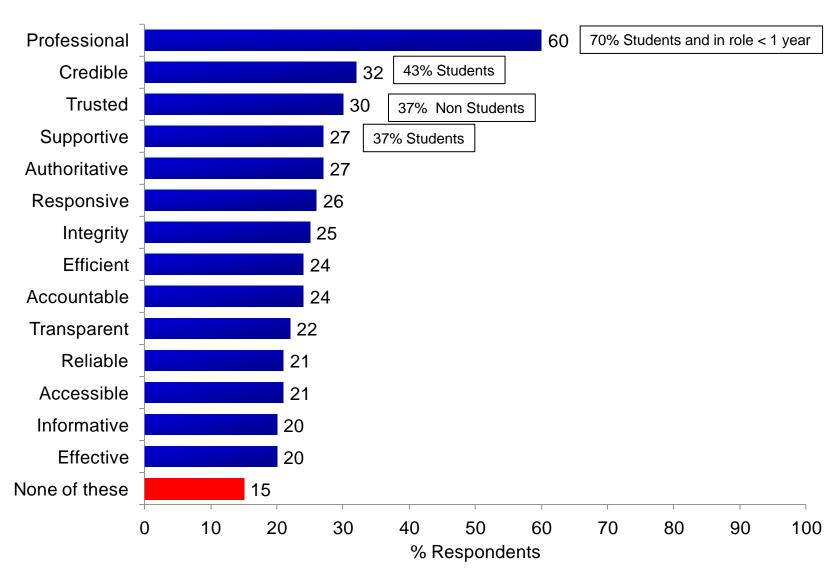
Few would speak critically of the HRA. Four in ten Researchers would speak highly of HRA while 22% would be critical of HRA/NRES, 20% critical of CAG

Q7/Q11 How favourable or unfavourable is your overall view of the HRA and its National Research Ethics Service/RECs/CAG?

Base: Researchers who applied to REC (153); Researchers who applied to CAG (20)

### 'Professional' chosen by six in ten Researchers to describe HRA and NRES

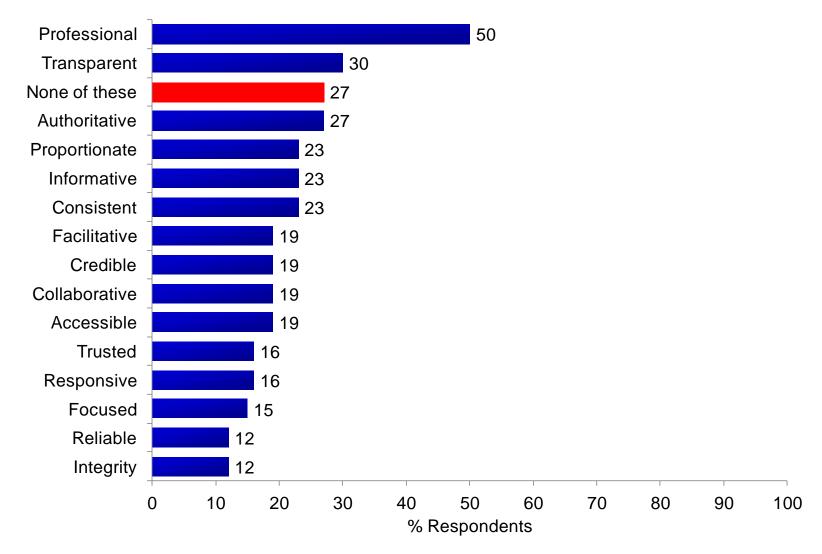




Q9 In your experience, please indicate which of the words below could be used to describe the HRA and its National Research Ethics Service. Please tick as many boxes as you think apply. Base: Researchers (156)

### 'Professional' also the most likely word chosen to describe the CAG



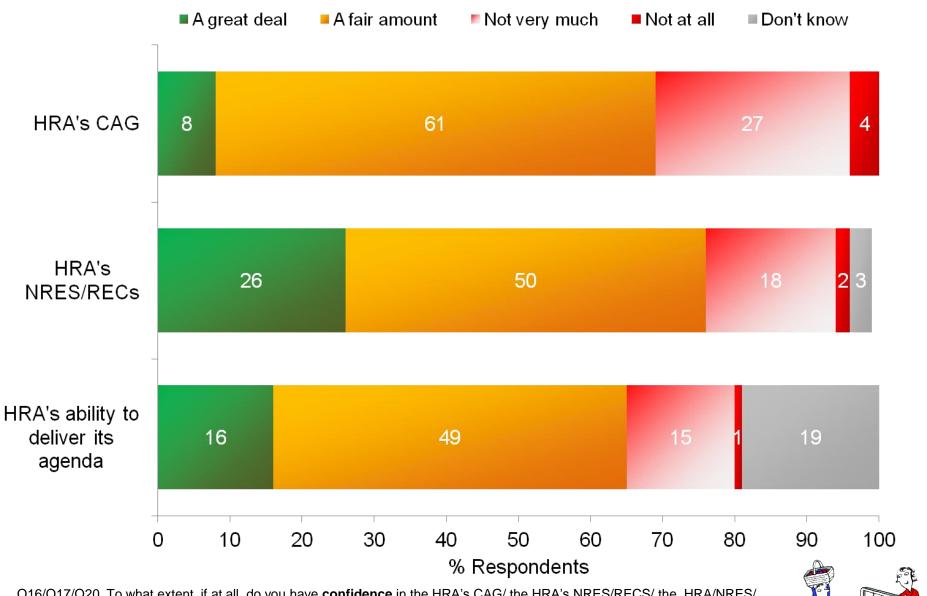


Q13 In your experience, please indicate which of the words below could be used to describe the HRA and its CAG. Please tick as many boxes as you think apply.

Base: Researchers who applied to CAG (20)

#### Evident lack of confidence in the HRA and NRES among some Researchers





Q16/Q17/Q20 To what extent, if at all, do you have confidence in the HRA's CAG/ the HRA's NRES/RECS/ the HRA/NRES/ the HRA's ability to deliver its agenda? Base: Researchers who applied to CAG (20)/Researchers who applied to REC (153)/

Researchers (156)

## Researchers feel most important activities not delivered effectively

**Accent** 

Most important but not generally seen as effectively delivered

Simplifying the approvals process for research in the NHS

Streamlining research governance or R&D approval

Continually improving the system for ethical review

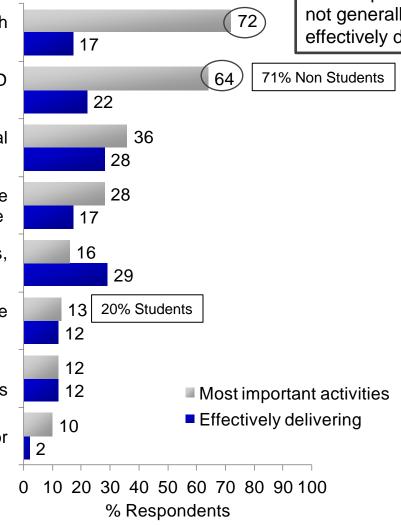
Working with other organisations to ensure joined up regulation, advice and guidance

Producing tools and guidance for researchers, including student researchers

Ensuring that the results of research are published and shared

Supporting access to patient information without consent with appropriate safeguards

Reducing the burden on your sector



Q14 From the list below, please select the top three most important activities which you think the HRA should be engaging in.

Q15 From the list below, please tick the activities which you think the HRA is effectively delivering. Please select as many activities as you think apply.

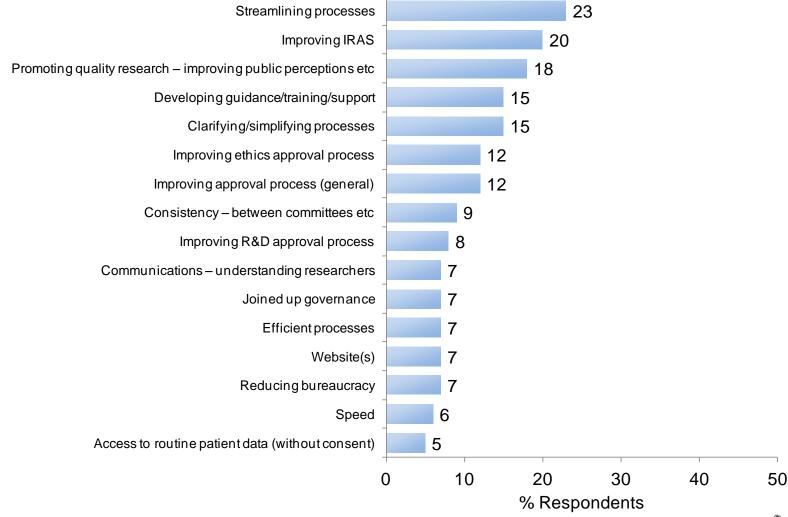
Base: All Researchers (156)





# Researchers see streamlining and improving application process as key focus in next few years





Q45 Thinking about the next few years, what two or three things do you think might be the most important for the HRA to focus on?

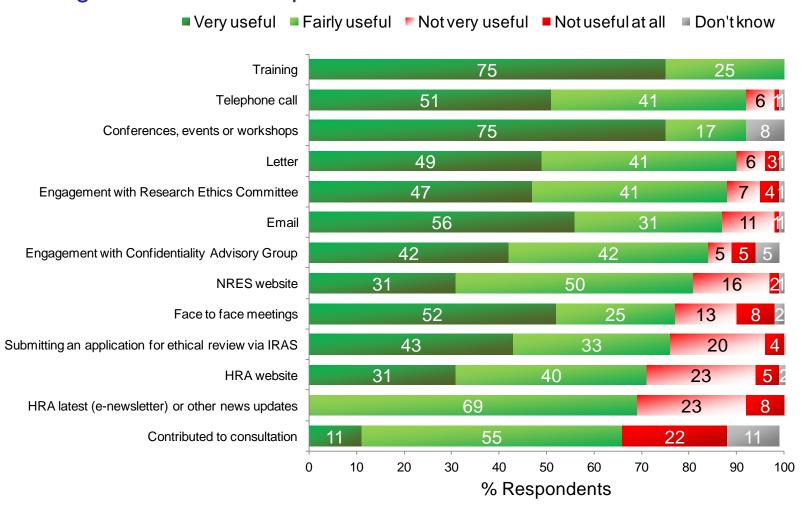
Base: All Researchers (156)





### Researchers find most of the communications useful, but more negative on some aspects





The improvements in communications most likely to be sought were:

- -More responsive/quicker
- -Consistency more reliable communication/information

Q24 How useful, if at all, do you personally find the following form(s) of communication with the HRA? Base: All those who used/received each

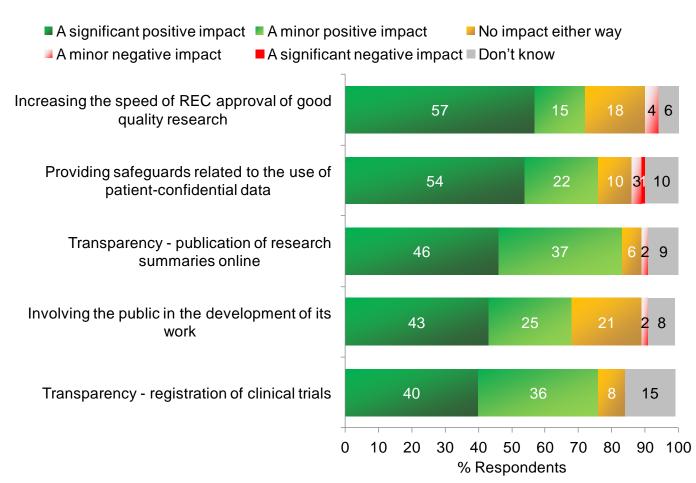




# It is believed that the changes the HRA is implementing will have a positive impact on public confidence



#### The vast majority see involving patients and the public as important



Q37 Thinking about the following changes implemented by the HRA, what level of impact, if any, do you think they will have on public confidence in research?

Base: All Researchers (156)

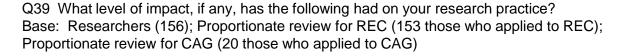




# On the whole, changes more likely to have impacted positively than negatively on research practice



■ A significant positive impact ■ A minor positive impact No impact either way A minor negative impact ■ A significant negative impact ■ Don't know Increasing the speed of REC approval of good quality research Proportionate review for REC Providing safeguards related to the use of patient-confidential data Encouraging the involvement of the public in the development of your research Proportionate review for CAG (currently being extended) Transparency - publication of research summaries online Transparency - registration of clinical trials Increased availability for meetings of Gene Therapy Advisory Committee % Respondents



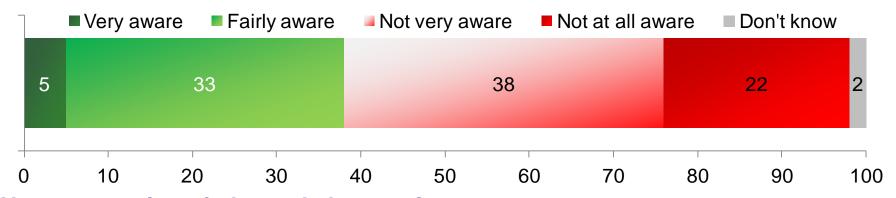




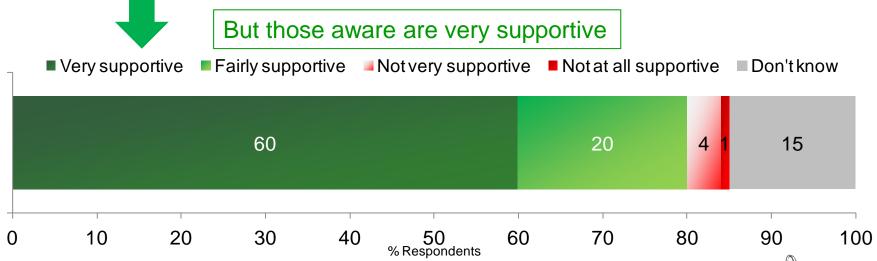
## Awareness of HRA's role in streamlining approvals not very high among Researchers



#### Awareness of HRA's role in streamlining REC and R&D approvals



#### How supportive of planned changes?



Q32 How well aware are you of the HRA's role in streamlining REC and R&D approvals? Base: Researchers (156)

Q33 How supportive are you of these planned changes?

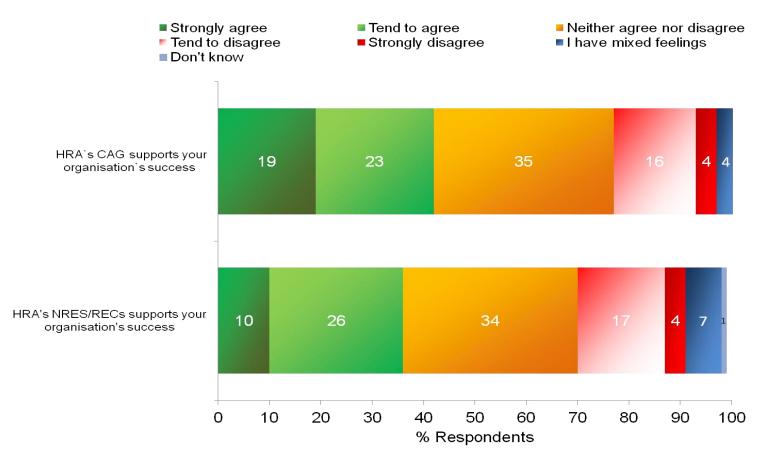
Base: Researchers aware of HRA's role in streamlining REC and R&D approvals (68)



### Views of Researchers are mixed regarding whether HRA and NRES support their organisation's success







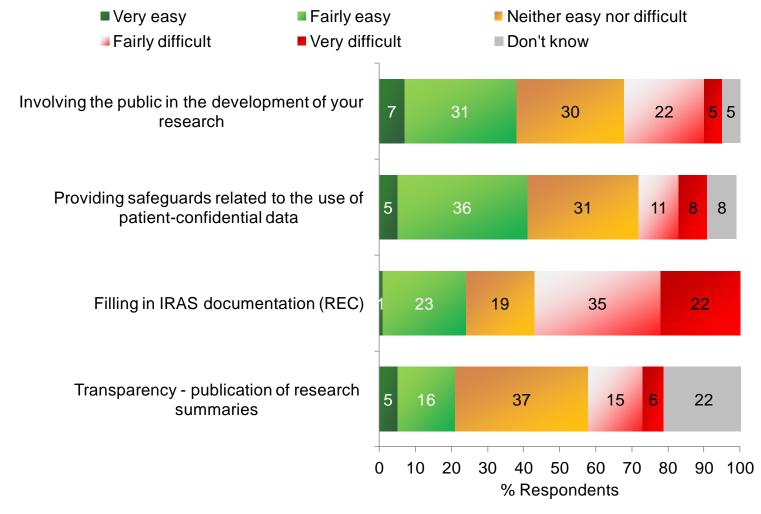
Very few Researchers believe that the HRA takes into account their views when making decisions that might affect the research community

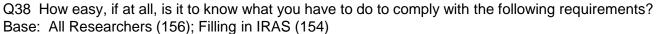




# Researchers have some issues with compliance, especially IRAS documentation















#### **KEY FINDINGS**

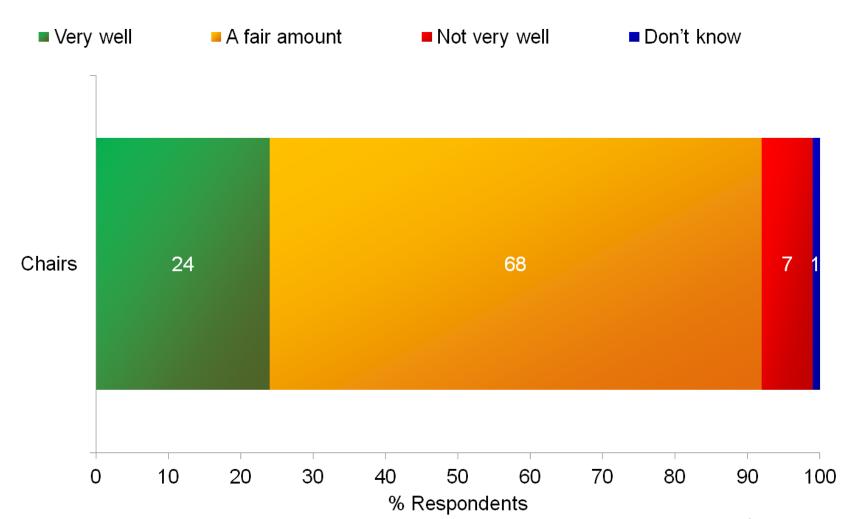
### Chairs



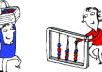


## One in four Chairs know what the HRA does "very well"



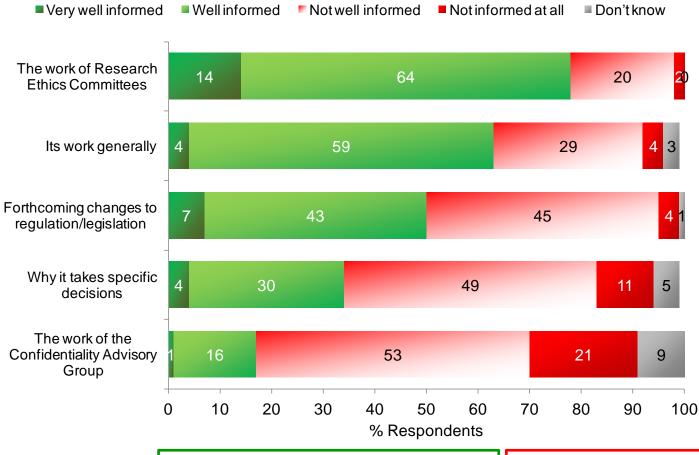


Q3 How well do you think you know what the HRA does? Base: Chairs (91)



#### Chairs feel well informed on certain aspects of the HRA's work but poorly informed in other areas





Q14 How well informed, if at all, do you feel HRA keeps you about...

Base: Chairs (91)

REC Chairs significantly more likely to feel 'well informed' for:

Why it takes specific decisions, forthcoming changes to regulations/legislation, the work of the Confidentiality Advisory Group

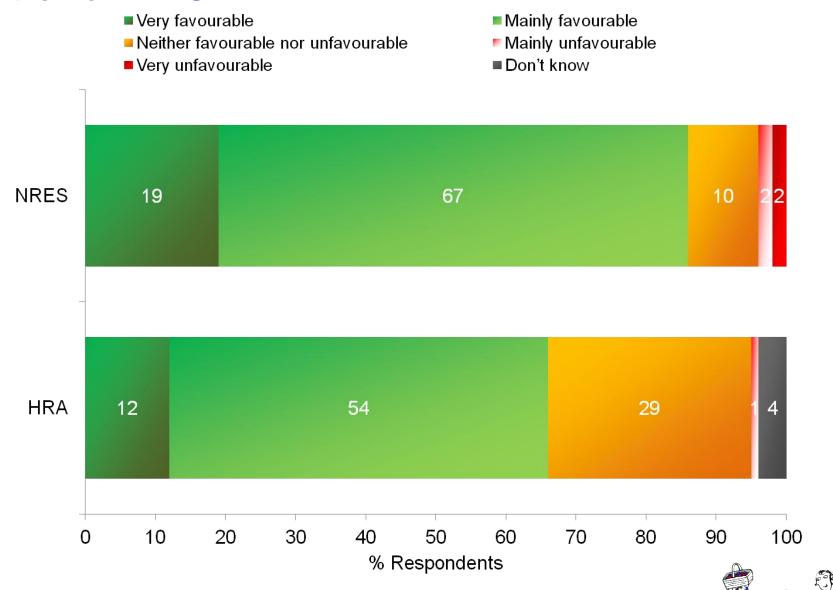
REC Vice Chairs significantly more likely to feel 'not well informed' for: Its work generally, forthcoming changes to regulations/legislation





#### Chairs are more neutral in their view of the HRA than of NRES



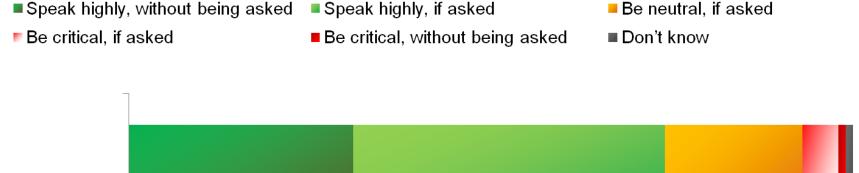


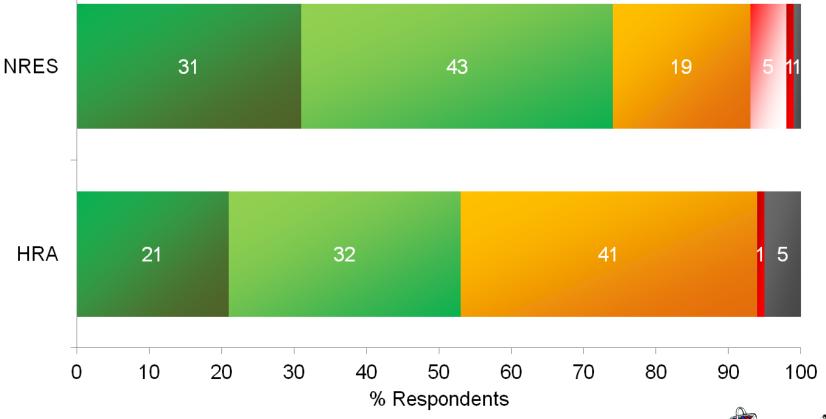
Q4. How favourable or unfavourable is your overall view of the HRA and its National Research Ethics Service/RECs?

Base: Chairs (91)

### Similarly, Chairs are less likely to speak highly of the HRA than of NRES



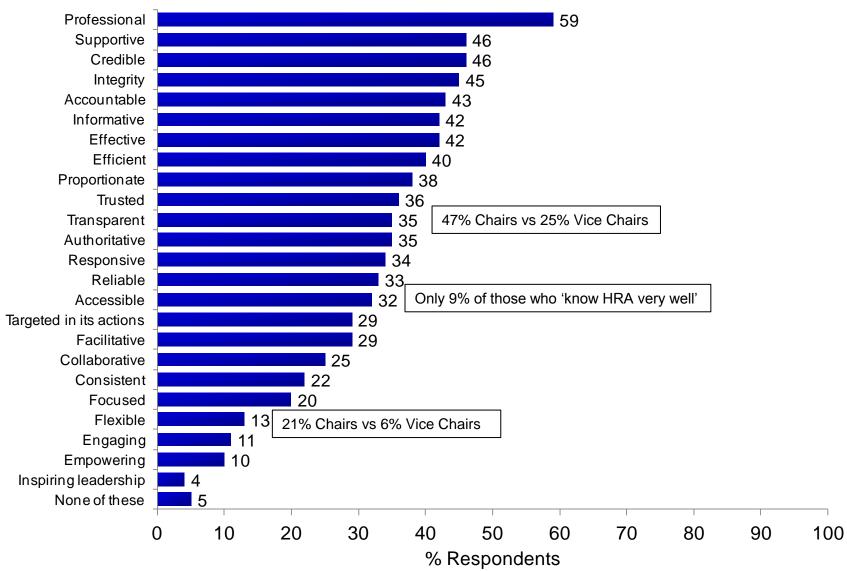




Q5. Which of these comes closest to describing how you would speak about the HRA and its National Research Ethics Service/RECs? Base: Chairs (91)

### 6 in 10 Chairs choose the word 'professional' to describe the HRA/NRES



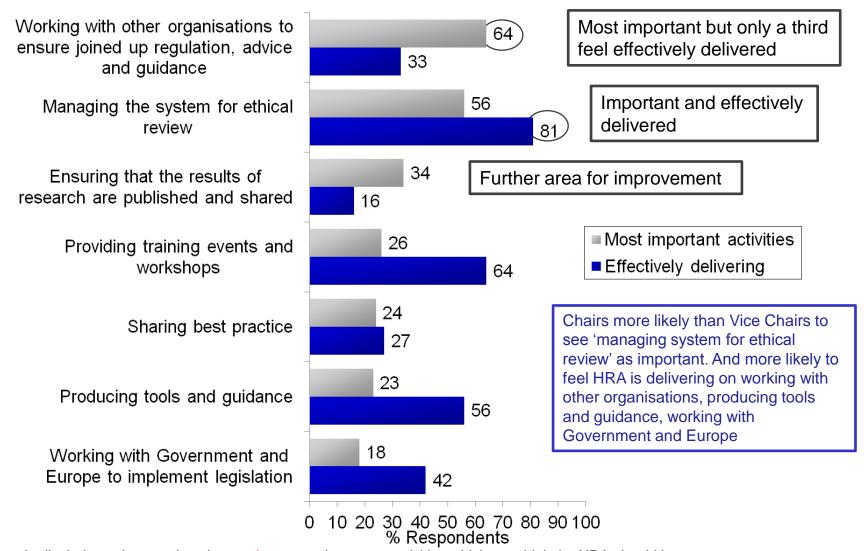


Q6 In your experience, please indicate which of the words below could be used to describe the HRA and its National Research Ethics Service. Please tick as many boxes as you think apply.

Base: Chairs (91)

### Chairs see the need for the HRA to work with other organisations more effectively





Q7 From the list below, please select the top three most important activities which you think the HRA should be engaging in.

Q8 From the list below, please tick the activities which you think the HRA is effectively delivering. Please select as many activities as you think apply.

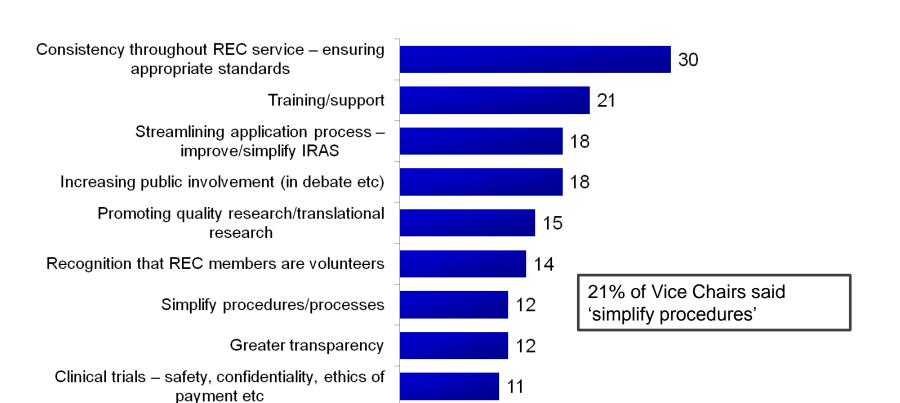
Base: Chairs (91)





#### What should future focus be on?





11

10

20

% Respondents

10

30

40

Q31 Thinking about the next few years, what two or three things do you think might be the most important for the HRA to focus on?

Increasing public awareness

EU legislation/implementation

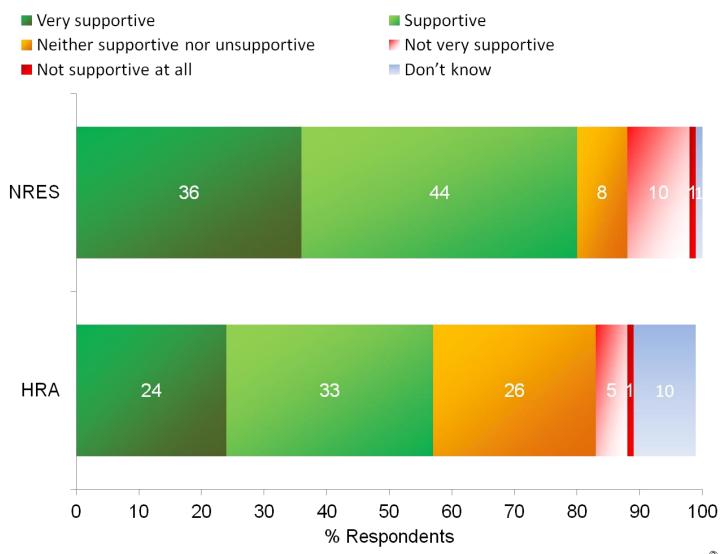
Base: All Chairs who gave an answer (73)



50

### 8 in 10 Chairs view NRES as supportive of their REC; 6 in 10 see the HRA as supportive





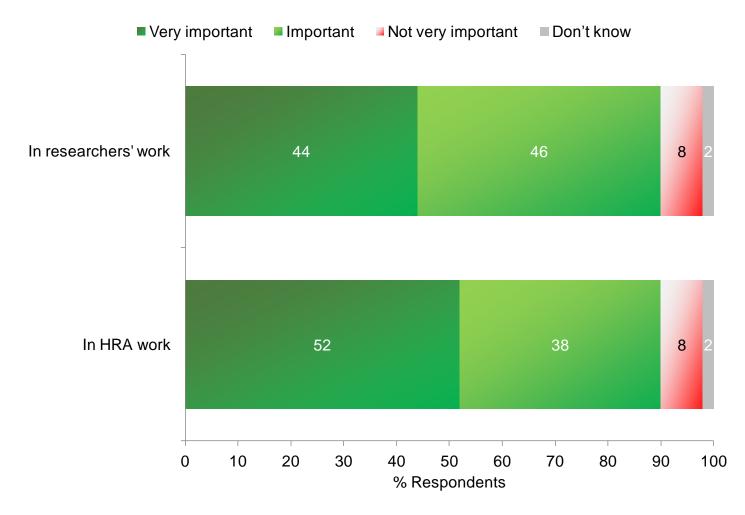
Q10. How supportive do you think the Health Research Authority (HRA)/NRES are in the work of your REC? Base: Chairs (91)





### Chairs too see involving patients and public as important





Q19 How important is it that **the HRA involves** patients and the public in its own work? Q20 How important is it that **researchers involve(s)** patients and the public in the design and development of their studies?

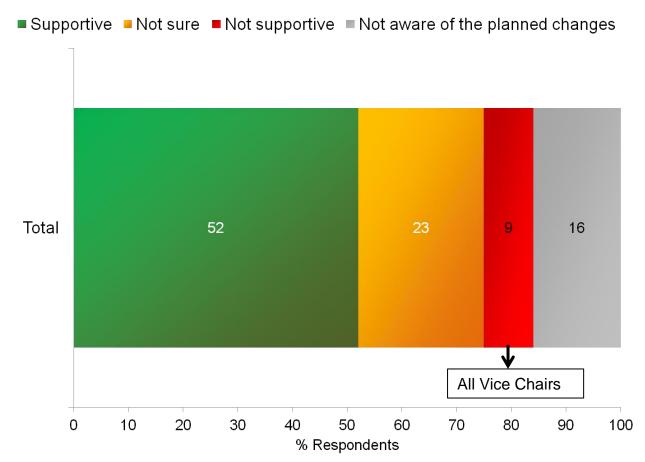
Base: All Chairs (91)





## Chairs generally supportive of HRA Approval streamlining





And the majority believe that the changes the HRA is implementing will have a positive impact on public confidence in research

Q28 How supportive are you of the HRA's planned changes to streamline REC and R&D approvals? Base: All Chairs (91)



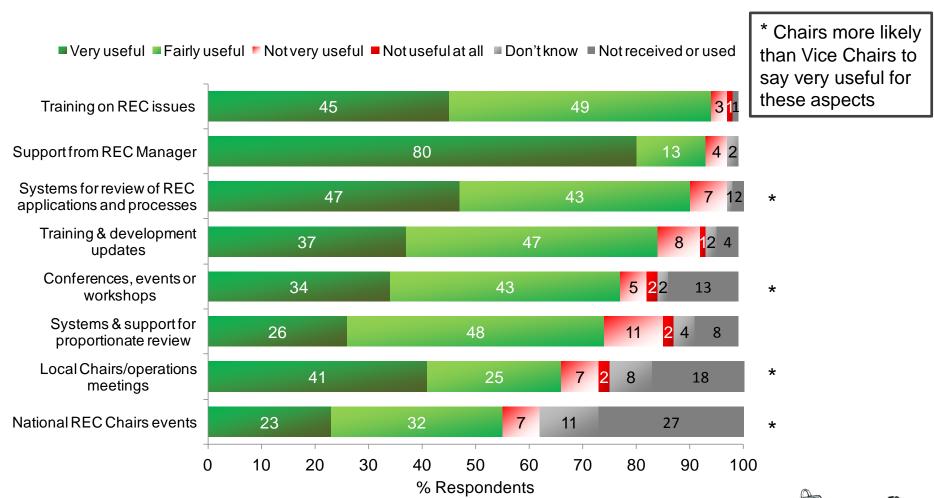


#### Where HRA provides support to Chairs, it's largely seen as useful





Support from REC Manager is overwhelmingly seen as very useful



Q13 How useful, if at all, do you personally find the following forms of support provided by the HRA?

Base: All Chairs (91)

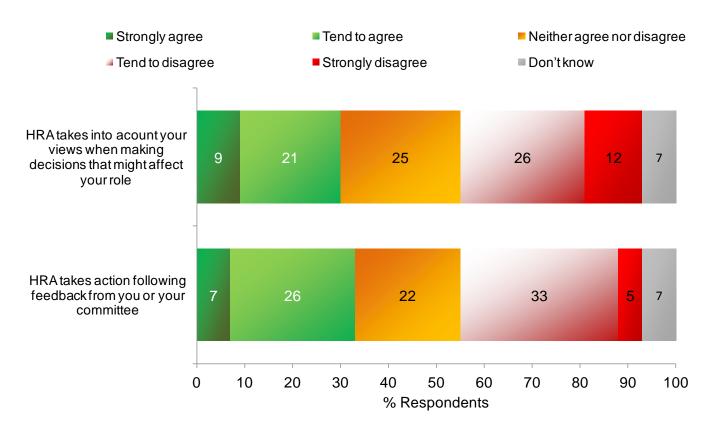




# Belief that the HRA takes into account their views and takes action following feedback is not very strong



Chairs more likely to agree strongly that HRA takes into account their views. Vice Chairs more likely to tend to disagree that HRA takes action following feedback



Q26 To what extent do you agree or disagree that the HRA takes into account your views when making decisions that might affect your role? (Chairs 91)

Q27 To what extent do you agree or disagree that the HRA takes action following feedback from you or your committee? (Chairs 91)

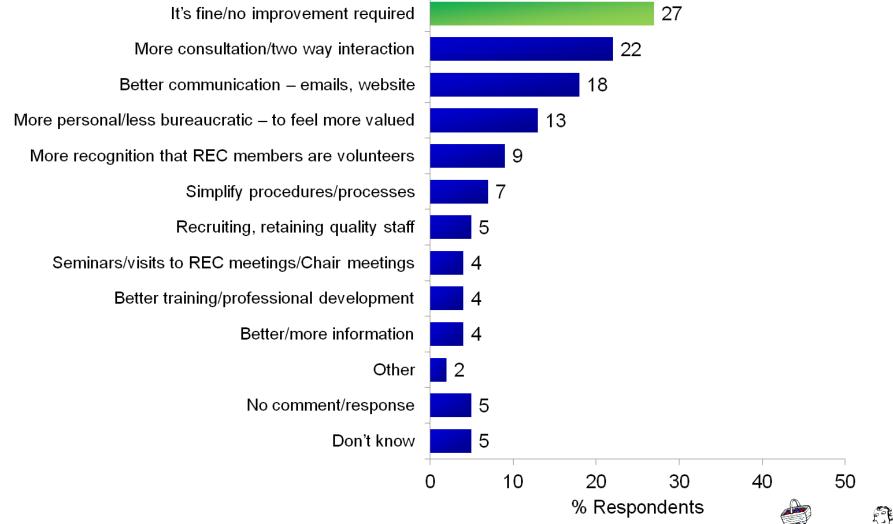




# One in four Chairs feel no improvement needed, but some looking for NRES to do more consultation and better communication







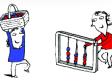
Q33 How, if at all, could the NRES improve its relationship with you? Base: All Chairs who gave an answer (55)



#### CONCLUSIONS







### Conclusions & Recommendations Public Omnibus



- Public confidence in health research shows improvement from 2013 and most people are positive about taking part in a health research study – although barriers to participation mean a third rule themselves out of taking part
- Knowledge of review by an ethics committee and involvement of patients increases the confidence the public has in health research studies
- ➤ The public continues to regard research funded by pharmaceutical companies with more scepticism than that funded by public sector or charities
- The HRA itself has a relatively low profile
- Communication to address concerns about taking part in research, including the amount of time and effort involved, privacy and data confidentiality, and the general understanding of what is involved, could increase participation
  - The HRA should also consider how it can improve the perceptions of lower SEG groups, minority ethnic members of the public, and younger people who may be less likely to participate

### Conclusions & Recommendations Key Opinion Leaders



- There is a good level of awareness of the HRA and its purpose and goals
- Key Opinion Leaders also have confidence in the HRA's ability to deliver
- It is seen to have been effective already in reducing approval times
- Key strengths are its leadership and people
- And the way it's collaborating with other bodies
- Some criticism of communications
- But they feel they are being consulted and listened to
- Overall, Key Opinion Leaders have very favourable views and goodwill towards the HRA



#### **Conclusions & Recommendations**

### £3



#### Researchers

- There is reasonable awareness of what the HRA does but slightly lower awareness with regard to the CAG. However there is good awareness of HRA's tools
- ➤ The HRA and NRES/RECs are viewed favourably overall and most likely to be described as 'professional' as was the CAG
- There is some lack of confidence in the HRA, especially the CAG, among Researchers
- There is an element of mismatch between what stakeholders believe the HRA is delivering effectively and what they feel are the most important activities.
  - ➤ For Researchers, simplifying the approvals process for research in the NHS and streamlining research governance or R&D approval are both very important but few feel the HRA is delivering on these
- Streamlining processes and improving IRAS head the list of issues Researchers would like HRA to focus on in the next few years



### Conclusions & Recommendations Researchers



- Researchers are generally positive about the HRA's communications but it is worth reviewing those which they feel are less useful
- Researchers are positive regarding the changes the HRA is implementing; they will have a positive impact on public confidence
- Researchers are not very aware of the HRA's role in streamlining REC and R&D approvals so there is some work to do in raising awareness as they are very supportive when they do know
- There is more to do with Researchers to convince them that the HRA is supporting their organisation
- Researchers evidently need further help with compliance and the difficulty in filling in IRAS documentation would be the priority
- A large minority need to be convinced that the HRA takes their views into account and actions their suggestions

### Conclusions & Recommendations Chairs



- As might be expected, Chairs are fairly knowledgeable about the HRA and favourable towards it
- Chairs also chose the term 'professional' to described HRA. 'Supportive' and 'Credible' were also high on the list
- Chairs are more likely than Researchers to view that the HRA effectively delivers what they believe to be the most important activities.
  - However, working with other organisations to ensure joined up regulation and ensuring results of research are published and shared need to be more effectively delivered
- Consistency throughout REC services was seen as an area for focus in the next few years
- There is a general consensus that it is important to involve patients and the public



### Conclusions & Recommendations Chairs



- Chairs are positive regarding the changes the HRA is implementing; they will have a positive impact on public confidence and will not impact negatively on research practice
- But they are not necessarily well-informed on all aspects of the HRA's work
- Chairs are generally supportive of the HRA's role in streamlining REC and R&D approvals
- ➤ Chairs see the HRA as supportive and the support provided to them is useful. The REC Managers deserve mentioning as 8 out of 10 Chairs find their support very useful
- One in four don't feel that the NRES needs to improve its relationship with them



# Thank you Any questions?



