

## Context

## Key Findings:

Public perceptions of health research
Key Opinion Leaders
Chairs
Researchers

## Conclusions



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## 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

* Accent
issues to inform comms


OBJECTIVES
> Evaluation of
> Confidence in HRA's role
> Effectiveness
> Views on policy issues
> Value for Money
> Satisfaction with REC, R\&D approvals
> HRA guidance and advice
$>$ Views on future issues

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

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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 *
- $\quad 40 \%$ 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

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\squareVery confident (4)
Not very confident (2)
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- Don't know


Of the public think health research is important

## 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 $A B$ 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


## 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

Views about the following people accessing your patient record?

- 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 $5 \%$.




## 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
- $\quad 42 \%$ of ABs and $35 \%$ of C1s feel 'very confident' if the study is reviewed by a Research Ethics committee, compared to $26 \%$ of C 2 s and $23 \%$ of $D E s$ (* $A B$ vs $C 1$ and $C 2$ 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*

Confidence in taking part in health research study if you knew it had been reviewed by a Research Ethics Committee


## 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*


# 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 ...



# 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



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

* Difference statistically significant at the 95\% confidence level

Main reasons willing to take part:

- Helping society ( $71 \%$ )
- Helping family or friends (45\%)
- Personal experience of illness or disease (36\%)



## 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
"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"

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
"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."

And it's felt to be doing a better job than a year ago


## 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
"Sometimes things change and I don't seem to be aware of it"
"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"
"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"
"I know that they have been successful in significantly reducing approval times for ethical approval and having more consistency around there"

## 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


## "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".> "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".

## 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

Accent
$\square$ A great deal

- A fair amount
- Not very much

■ Not at all


## Researchers feel most important activities not delivered effectively



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



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


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

$\square$ A significant positive impact $\square$ A minor positive impact $\quad$ No impact either way
$\square$ A minor negative impact $\quad$ A significant negative impact $\square$ Don't know


Q39 What level of impact, if any, has the following had on your research practice?
Base: Researchers (156); Proportionate review for REC (153 those who applied to REC);
Proportionate review for CAG (20 those who applied to CAG)


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?



## 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



Q38 How easy, if at all, is it to know what you have to do to comply with the following requirements?
Base: All Researchers (156); Filling in IRAS (154)


## KEY FINDINGS

## Chairs



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


- Very well
$\square$ A fair amount
- Not very well
- Don't know



# 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 Vice Chairs significantly more likely to feel 'not well informed' for: Its work generally, forthcoming changes to regulations/legislation
changes to regulations/legislation, the work of the Confidentiality Advisory Group

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

- Very favourable
$\square$ Neither favourable nor unfavourable
- Very unfavourable
- Mainly favourable
-Mainly unfavourable
- Don't know



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

■ Speak highly, without being asked
Be critical, if asked

- Speak highly, if asked
- Be critical, without being asked
- Be neutral, if asked
- Don't know


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

 and guidance
Managing the system for ethical review


Ensuring that the results of
research are published and shared


33
Most important but only a third feel effectively delivered

Important and effectively delivered

## What should future focus be on?



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

■ Very supportive

- Neither supportive nor unsupportive

■ Not supportive at all

- Supportive

Not very supportive

- Don't know



## 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

$■$ Supportive $\square$ Not sure $\square$ Not supportive $■$ Not aware of the planned changes



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



# 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 


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## 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

## 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 <br> 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?



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