



The Human Tissue Authority (HTA) Public Engagement

Quantitative Research Report
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Prepared for:

Human Tissue Authority (HTA)

Prepared by:

*Research Works Limited
Regency House
The Quadrant
219a Hatfield Road
St Albans, Herts
AL1 4TB
all@researchworks.co.uk
Tel: 01727 893 159*

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1. Executive summary

The Human Tissue Authority (HTA) has commissioned research into public awareness of, and interest in, the HTA and the areas that the HTA regulates. The research study comprised qualitative focus groups and a general public online survey.

- Quantitative research supported the qualitative findings regarding public awareness of the Human Tissue Authority, with recognition low at 10%;
 - Awareness was higher amongst older age groups and amongst higher socio-economic groups.
- The 3 areas of the HTA's activities that were perceived most important across both qualitative and quantitative research included:
 - organ donation (86%);
 - the study of human tissue to improve understanding of health and disease (58%);
 - and the use of human bodies to teach students (50%)
- When discussed in the qualitative research, making sure that body parts are not bought and sold and the need for regulation after a scandal (some mentioned a scandal in Liverpool) were felt to be important.
- Qualitatively, post-mortem examination was perceived be an area of high importance. In the quantitative results, almost half (47%) considered post-mortem examination important
- 45% considered the use of therapeutic use of human tissue and cells important, which reflects the qualitative findings – however, it was also felt to be an area that lacked clarity;
- The regulation of display in public was considered least important of the activities shown both qualitatively and quantitatively (15%).
- The qualitative research highlighted the importance of making sure that body parts are not bought and sold and the need for regulation after a scandal (although only a few mentioned a scandal in Liverpool);
 - In the quantitative research, respondents prioritised monitoring the performance of organisations.
- Quantitative research confirmed findings from the qualitative element that the public are confident in the HTAs current approach – with 61% expressing confidence.
- Confidence scores dropped in response to a potential change in approach involving fewer on-site inspections, instead relying more on intelligence gathered from third parties and self-reporting from organisations.
- If a serious failure is found by HTA, almost half (43%) clearly think that the 'HTA and the establishment should work together to fix the problem and the HTA should **publish the report on their website so the public can find out about it if they wish**';
 - Almost a third (31%) think the HTA should **publish the report and share it with the media to ensure that the public are aware of the issues**;
 - Finally, only a small proportion (16%) thought **'it was not necessary to share this information with the public at the time'**.

2. Research Methodology and Sample

The following report details the findings from an online survey of a nationally representative sample of 1,000 adults across England, Wales and Northern Ireland.

The following details our sample breakdown:

Gender:	Age:		Socio-economic group
Male – 48%	18-24 years	12%	ABC1 47%
Female 52%	25-34 years	17%	C2DE 48%
	35-44 years	18%	Prefer not to say 5%
	45-54 years	18%	
	55-64 years	15%	
	65+ years	21%	

The fieldwork was conducted between 28th July and 2nd August 2017.

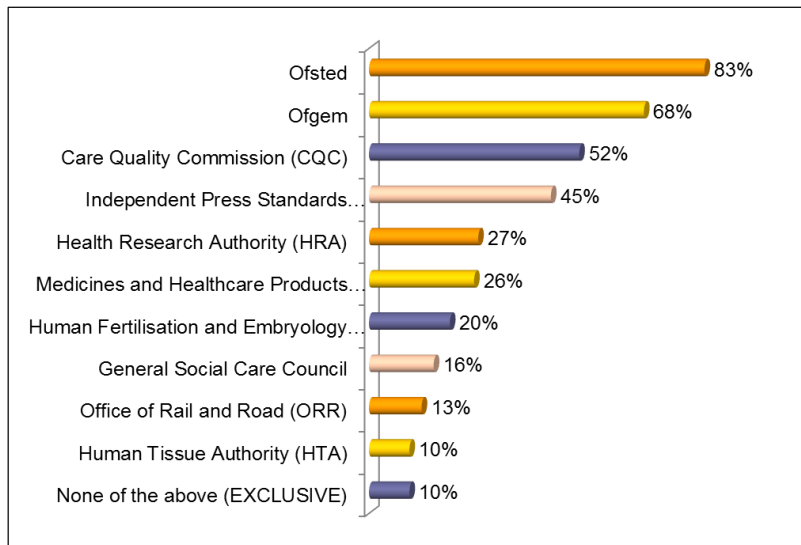
3. Main findings

3.1 Awareness of UK Regulators



Awareness of UK Regulators

Q1. I'm going to show you a list of UK regulators. Which of the following regulators have you heard of (if any)? Multicode



Base: All (1,000)

1

Ofsted (83%), Ofgem (68%) and CQC (52%) emerged as the most recalled regulators. Awareness of the Human Tissue Authority was lowest at 10% recognition. Awareness of HTA was higher amongst higher socio-economic groups ABC1 at 13%. Overall, the data reveals that awareness of regulators generally was higher amongst older age groups and amongst higher socio-economic groups.

1.2 Public prioritisation of HTA areas of activity

Public prioritisation of HTA activities to ensure standards are met

Q3. Here is a list of all the activities the Human Tissue Authority undertakes in order to ensure that standards are being met. In order of importance, which THREE do you think are most important to ensure standards are met? **PLEASE RANK YOUR TOP 3, WHERE 1 IS THE MOST IMPORTANT, 2 IS THE NEXT MOST IMPORTANT AND 3 IS THE NEXT MOST IMPORTANT**

	1 st	2 nd	3 rd	Overall
Licensing new organisations who meet the appropriate standards	25%	14%	14%	53%
On-site inspection of premises	20%	17%	19%	56%
Monitoring organisation's performance (via a comprehensive intelligence system) and highlighting any serious concerns	25%	25%	17%	67%
Collecting data from organisations who report on their own performance	5%	9%	9%	23%
Using effective enforcement powers against organisations who do not meet standards	16%	25%	24%	64%
Providing advice and guidance to organisations	10%	10%	18%	38%

Base: All (1,000)

3

Note: the 'overall' percentage is a culminative total of scores valued as 1, 2 or 3

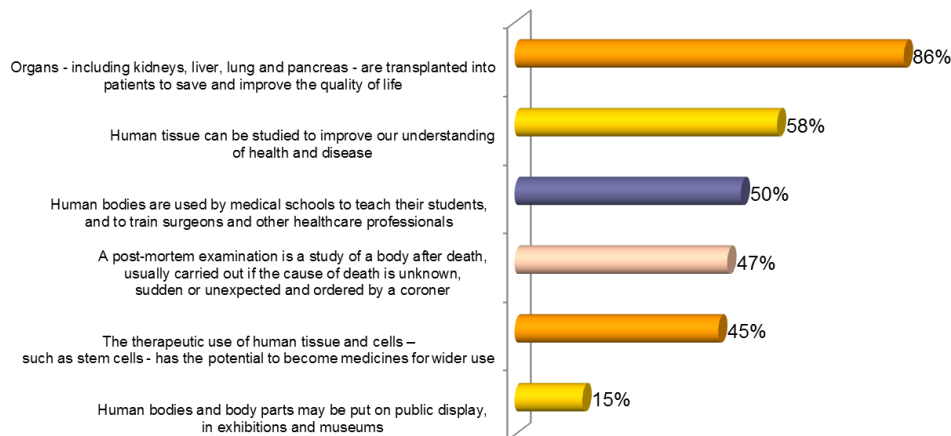
The top three most important areas of the HTA's activities included: organ donation (86%), the study of human tissue to improve understanding of health and disease (58%) and the use of human bodies to teach students (50%). Women in particular thought organ donation was important (89%) as did those from socio-economic group ABC1 (89%).

The remaining three areas were also clearly important suggesting the public values all of HTA's areas of activity. Almost half (47%) considered post-mortem examination important and 45% considered the therapeutic use of human tissue and cells important. It is interesting to note that the rating for this activity was higher amongst older age groups, 45 years plus.

While the regulation of display in public was considered least important of the activities shown at 15%; it was rated higher amongst men (20%) and younger age groups (25%) under 34 years.

Public prioritisation of HTA areas of activity

Q2. The Human Tissue Authority is a regulator which regulates organisations that remove, store and use human tissue for research, medical treatment, post-mortem examination, education and training, and display in public. The Human Tissue Authority also gives approval for organ and bone marrow donations from living people. Which do you think are the 3 most important areas of activity?



Base: All (1,000)

2

3.3. Public prioritisation of HTA activities to ensure standards are met

Our sample ranked the activities HTA undertakes to ensure that standards are met. The sample provided a ranking of 1 to 3 in terms of importance (with 1 being most important).

The public clearly prioritise ‘monitoring organisation’s performance’ as the most important area of HTA activities with a quarter (25%) giving this activity a number one ranking with an overall score of (67%). A quarter (25%) gave ‘licensing new organisations who meet the appropriate standards’ a number one ranking with an overall score of 53%.

Finally, ‘using effective enforcement powers’ was ranked number one in terms of importance by a small proportion at 16% of our sample, the overall score of three quarters (64%) indicates a higher priority for this activity. ‘On-site inspections’ were consistently rated as important with 20% ranking it as the most important and an overall score of (56%).

‘Providing advice and guidance to organisations’ was ranked relatively lower with an overall score of 38%. ‘Collecting data from organisations’ was ranked lowest in importance by the public with only 5% ranking it as most important and an overall score of 23%.

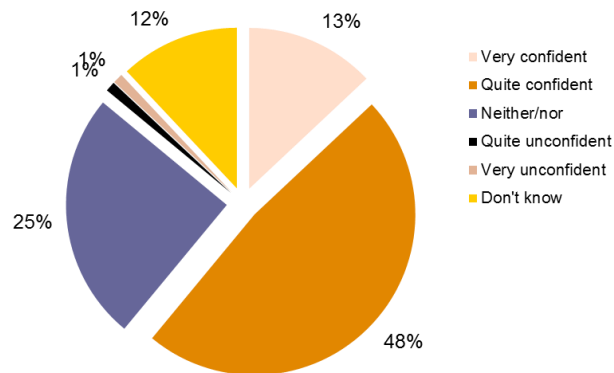
3.4 Confidence in current levels of activity undertaken by HTA to ensure standards are met

Almost two thirds (61%) of the public are confident in the HTA's current approach, although it is worth noting that most are 'quite confident' (48% of the total) rather than definitely 'very confident' (13%). Responses from the ABC1 group showed higher levels of confidence, with a 67% overall confidence score.

Confidence in current levels of activity undertaken by HTA to ensure standards are met

Q4a&4b. Currently, the Human Tissue Authority works with regulated establishments to ensure they meet standards by a combination of on-site inspections, monitoring and reporting. If organisations do not meet standards, the Human Tissue Authority works with them to bring them up to standard through the creation of an improvement plan which the organisation must follow. The organisation will then be inspected again at a later date.

Q4a. How confident do you feel about the way in which the Human Tissue Authority currently regulates organisations?



Base: All (1,000)

4

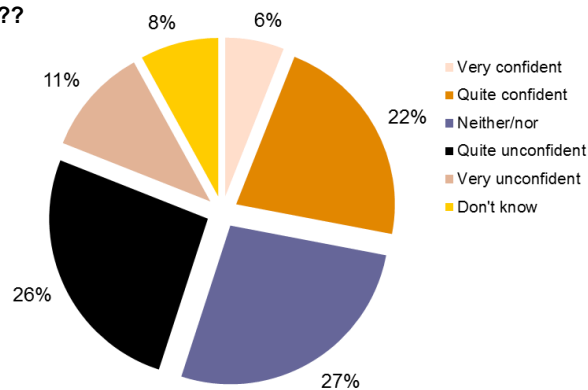
3.5 Confidence if HTA changed its approach to ensuring standards are met

Confidence scores clearly drop in response to a potential change in approach involving fewer on-site inspections, instead relying more on intelligence gathered from third parties and self-reporting from organisations. Confidence in this proposed new approach drops to a quarter (28%) from almost two thirds confident in the current approach (61%).

Confidence if HTA changed its approach to ensuring standards are met

Q4a&4b. Currently, the Human Tissue Authority works with regulated establishments to ensure they meet standards by a combination of on-site inspections, monitoring and reporting. If organisations do not meet standards, the Human Tissue Authority works with them to bring them up to standard through the creation of an improvement plan which the organisation must follow. The organisation will then be inspected again at a later date.

Q4b. If the Human Tissue Authority changed its approach, and had fewer on-site inspections, instead relying more on intelligence gathered from third parties and self-reporting from organisations, how confident would you feel about the way in which the Human Tissue Authority regulates organisations??



Base: All (1,000)

5

3.6 Approach to serious failures

If a serious failure is found by HTA, almost half (43%) clearly think that the 'HTA and the establishment should work together to fix the problem and the HTA should **publish the report on their website so the public can find out about it if they wish**'.

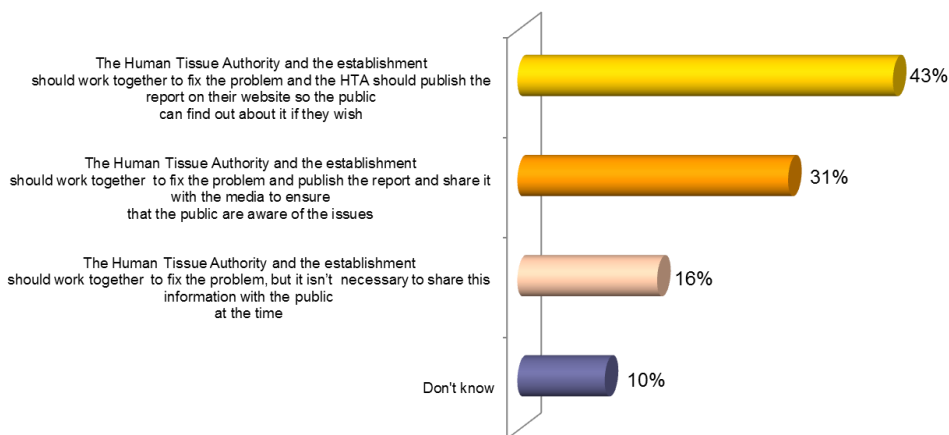
Almost a third (31%) think 'HTA and the establishment should work together to fix the problem and the HTA should **publish the report and share it with the media to ensure that the public are aware of the issues**'.

Finally, only a small proportion (16%) thought '**it was not necessary to share this information with the public at the time**'.



Approach to serious failures

Q5. When the Human Tissue Authority discovers a minor or major problem during an inspection, they work with the establishment to bring them up to standard, share learning from any serious incidents so they don't happen again and so that others can learn from the experience, and in the most serious cases, can take further regulatory action e.g. removing a licence. When serious failures are found, what should happen? **SINGLE CODE**



Base: All (1,000)

6

Appendix – Final Questionnaire

<p style="text-align: center;">HUMAN TISSUE AUTHORITY – ONLINE PANEL SURVEY QUESTIONNAIRE DRAFT 7</p>
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S1. You are...

Male

Female

S2. How old are you?

Less than 18 years old CLOSE

18-24 years old

25-34 years old

35-44 years old

45-54 years old

55-64 years old

65 years old or more

S4. What is the occupation of the head of the household?

SINGLE CODE

1. Higher managerial, administrative, professional e.g. Chief executive, senior civil servant, surgeon RECODE: A
2. Intermediate managerial, administrative, professional e.g. bank manager, teacher RECODE: B
3. Supervisory, clerical, junior managerial e.g. shop floor supervisor, bank clerk, sales person RECODE: C1
4. Skilled manual workers e.g. electrician, carpenter RECODE: C2
5. Semi-skilled and unskilled manual workers e.g. assembly line worker, refuse collector, messenger RECODE: D
6. Casual labourers, pensioners, unemployed e.g. pensioners without private pensions and anyone living on basic benefits, student, full time carer, homemaker RECODE: E
7. Prefer not to say

S5. Which region of the United Kingdom do you live in?

SINGLE CODE

1. London / Greater London
2. South East England
3. South West England

4. East of England
5. East Midlands
6. West Midlands
7. Yorkshire & Humber
8. North East England
9. Wales
10. Scotland
11. Northern Ireland

Q.1 I'm going to show you a list of UK regulators.

A regulator is an official body that makes certain that the organisations who operate within a sector (e.g. electricity supply, financial services, schools) work effectively and fairly.

Which of the following regulators have you heard of (if any)? **MULTICODE**

- | | |
|--|--------------------------|
| Care Quality Commission (CQC) | <input type="checkbox"/> |
| General Social Care Council | <input type="checkbox"/> |
| Human Tissue Authority (HTA) | <input type="checkbox"/> |
| Independent Press Standards Organisation (IPSO) | <input type="checkbox"/> |
| Medicines and Healthcare Products Regulatory Agency (MHRA) | <input type="checkbox"/> |
| Office of Rail and Road (ORR) | <input type="checkbox"/> |
| Ofgem – the office of the gas and electricity markets | <input type="checkbox"/> |
| Ofsted – the Office for Standards in Education, Children's Services and Skills | <input type="checkbox"/> |
| Human Fertilisation and Embryology Authority (HFEA) | <input type="checkbox"/> |
| Health Research Authority (HRA) | <input type="checkbox"/> |
| None of the above (EXCLUSIVE) | <input type="checkbox"/> |

Q.2 The Human Tissue Authority is a regulator which regulates organisations that remove, store and use human tissue for research, medical treatment, post-mortem examination, education and training, and display in public. The Human Tissue Authority also gives approval for organ and bone marrow donations from living people.

Here are all areas that the Human Tissue Authority regulates. Which do you think are the 3 most important areas of activity? **SELECT 3.**

A	<p><i>Human tissue can be studied to improve our understanding of health and disease.</i></p> <ul style="list-style-type: none"> • The Human Tissue Authority licenses organisations that remove and store tissue for scientific research. 	
B	<p><i>Human bodies are used by medical schools to teach their students, and to train surgeons and other healthcare professionals.</i></p> <ul style="list-style-type: none"> • The Human Tissue Authority licenses and inspects organisations, such as medical schools, that carry out these activities. • The Human Tissue Authority also provides the public with support and information about body donation. 	
C	<p><i>Human bodies and body parts may be put on public display, in exhibitions and museums.</i></p> <ul style="list-style-type: none"> • The Human Tissue Authority ensures that bodies and tissue from the deceased that are displayed to the public are treated with dignity and respect, and licenses any organisation involved in putting human bodies and body parts on public display 	
D	<p><i>Organs – including kidneys, liver, lung and pancreas – are transplanted into patients to save and improve the quality of life.</i></p> <ul style="list-style-type: none"> • The Human Tissue Authority licenses organisations to ensure the quality and safety of organs that are intended for transplantation. • The Human Tissue Authority also regulates, through an independent assessment process, the donation of organs from living people. The Human Tissue Authority ensures that valid consent has been given so that those donating understand any risks, donate of their own free will and that no reward is sought or offered. • For organ donation from deceased people, the Human Tissue Authority also oversees the legal consent requirements by providing advice and guidance to professionals 	
E	<p><i>The therapeutic use of human tissue and cells - such as stem cells - has the potential to become medicines for wider use.</i></p> <ul style="list-style-type: none"> • The Human Tissue Authority licenses organisations to ensure the quality and safety of tissue and cells used to treat 	

	patients, from donation through to use in treatment.	
F	<p><i>A post-mortem examination is a study of a body after death, usually carried out if the cause of death is unknown, sudden or unexpected and ordered by a coroner.</i></p> <ul style="list-style-type: none"> • The Human Tissue Authority licenses and inspects mortuaries where <i>post-mortem</i> examinations take place. The Human Tissue Authority also helps mortuaries improve the standards of care they provide, so that the public can have confidence that deceased people are treated with dignity and respect. • The Human Tissue Authority also provides advice and information to the public to help them make decisions about what should happen to organs and tissue samples that were removed for further examination. 	

Q.3 Here is a list of all the activities the Human Tissue Authority undertakes in order to ensure that standards are being met. In order of importance, which THREE do you think are most important to ensure standards are met?

PLEASE RANK YOUR TOP 3, WHERE 1 IS THE MOST IMPORTANT, 2 IS THE NEXT MOST IMPORTANT AND 3 IS THE NEXT MOST IMPORTANT

Licensing new organisations who meet the appropriate standards

On site inspection of premises

Monitoring organisations' performance (via a comprehensive intelligence system) and highlighting any serious concerns

Collecting data from organisations who report on their own performance

Using effective enforcement powers against organisations who do not meet standards

Providing advice and guidance to organisations

Currently, the Human Tissue Authority works with regulated establishments to ensure they meet standards by a combination of on site inspections, monitoring and reporting. If organisations do not meet standards, the Human Tissue Authority works with them to bring them up to standard through the creation of an improvement plan which the organisation must follow. The organisation will then be inspected again at a later date.

Q.4a How confident do you feel about the way in which the Human Tissue Authority currently regulates organisations?

- Very confident
- Quite confident
- Neither/nor
- Quite unconfident
- Very unconfident
- Don't know

Q4b. If the Human Tissue Authority changed its approach, and had fewer on-site inspections, instead relying more on intelligence gathered from third parties and self-reporting from organisations, how confident would you feel about the way in which the Human Tissue Authority regulates organisations?

- Very confident
- Quite confident
- Neither/nor
- Quite unconfident
- Very unconfident
- Don't know

Q5. When the Human Tissue Authority discovers a minor or major problem during an inspection, they work with the establishment to bring them up to standard, share learning from any serious incidents so they don't happen again and so that others can learn from the experience, and in the most serious cases, can take further regulatory action e.g. removing a licence.

When serious failures are found, what should happen? **SINGLE CODE**

The Human Tissue Authority and the establishment should work together to fix the problem, but it isn't necessary to share this information with the public at the time

The Human Tissue Authority and the establishment should work together to fix the problem and the HTA should publish the report on their website so the public can find out about it if they wish

The Human Tissue Authority and the establishment should work together to fix the problem and publish the report and share it with the media to ensure that the public are aware of the issues

Other (please specify)

Don't know