

IDEA

Please think about the care you receive at/ from _____ and answer the following questions. Please choose only one answer for each question.

1. Do people here treat you with dignity?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

2. Do people here treat you with respect?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

3. Do people here treat you as an individual?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

4. Do people here treat you as if you are important?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

5. Are you made to feel silly or stupid here?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

6. Do people here involve you in decisions about your care?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

7. Are you ignored here?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

8. Do people here talk down to you?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

9. Do people look at you when they speak to you?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

10. Do people here talk to you in a way that you can understand?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

11. Are your views ignored when decisions need to be made?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

12. Do people here show an interest in you?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

13. Do people here take time to get to know you?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

14. Do people here make assumptions about you?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

15. Do people here help you make decisions for yourself?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

16. Are you able to choose how you spend your time?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

17. Do you have to do what you are told here?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

18. Do people here know who's important to you and respect this?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

19. Are people you trust involved in decisions about your care when you need them to be?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

20. Do people here give you the time to do things?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

21. Do people here seem to understand your problems?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

22. Do people here take you seriously?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

23. If you get angry or upset do you think it will be held against you?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

24. Are you treated fairly here?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

25. Do people here help you live as normal a life as possible?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

26. Do people here respect your choices in how you want to live your life?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

27. Do people treat you differently now?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

28. Are you supported to do lots of the things you used to do?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

29. Do you still have contact with the people who are important to you?

Yes	Sometimes	No	Couldn't Answer
1	2	3	9

Care Plan Audit

Instructions for use:

Delete the appropriate response for each of the listed items to record if there is/is not evidence of the item in the care plan. Write any other comments in the space provided.

Patient Identifier:

.....

Date of admission:

.....

Date of discharge:

.....

1. General Items	Please circle appropriate answer	Comments:
Existence of a care plan?	Yes No	
Type of documentation	Paper Electronic Both	
Named Signed Dated	Yes/No Yes/No Yes/No	
Care plan completed by (please only state profession)		_____
Review date of care plan	Yes No	
End date of care plan (if applicable)	Yes No	
Diagnosis	Yes No	
Unexplained jargon/abbreviations	Yes No	If present how many occurrences:
Risk Assessment	Yes No	
Risk Management Plan	Yes No	
Goals Action Plan	Yes No	
Discharge Plan	Yes No	
Understanding of why they are on the ward/in the care home	Yes No	
Deprivation of Liberty Safeguards	Yes No	
Mental Capacity Act decisions	Yes No	

Mental Health Act Status	Yes No
Collaboration – mention of who was involved in creating the care plan	Yes No
If yes who was involved:	
Person with dementia	Yes/No
Relative/Family member	Yes/No
Professional	Yes/No
Other	Yes/No
Was the person with dementia asked if they wanted a copy	Yes No
Who else has copies:	
Person with dementia	Yes/No
Relative/Family member	Yes/No
Professional	Yes/No
Other	Yes/No
Person with dementia's preferred name recorded	Yes No
Preferred language recorded	Yes No
Any reference to Human Rights/FREDA	Yes No
Record any instances of Human Rights language:	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/>

2. Physical Health	Yes/No	Comments:
Current health issues	Yes No	
List of treatments	Yes No	
Current weight/BMI – happy with this?	Yes No	
Smoking	Yes No	Amount per day:
Alcohol consumption	Yes No	Amount per day:
Blood pressure recorded	Yes No	
Do they wear glasses	Yes No	
Do they use a hearing aid	Yes No	
Special needs: (Eating, drinking, communication, moving about, using the toilet, sleeping etc)	Yes No	
Pain	Yes No	Where:
Risk of falling	Yes No	
Other Comments:		<hr/> <hr/> <hr/> <hr/> <hr/> <hr/>

3. Mental Health	Yes/No	Comments:
Depressed feelings	Yes No	

(Any formal assessments e.g. Cornell Scale for Depression in Dementia)	
Anxious feelings	Yes No
(Any formal assessments e.g. Beck Anxiety Inventory)	
Experience of other unpleasant feelings	Yes No
Particular symptoms relevant to individual's diagnosis	Yes No
Other Comments:	
<hr/> <hr/> <hr/> <hr/> <hr/> <hr/>	

4. Cognitive Ability	Yes/No	Comments:
Visual processing problems	Yes No	
Ability to manage personal care	Yes No	
Memory issues	Yes No	
Communicating issues	Yes No	
Difficulties with planning/judging/controlling	Yes No	

5. Capacity for doing	Yes/No	Comments:
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Predominant way of engaging with the world at the current time

Yes
No

Please circle person's level of ability:

Eating/Drinking

Automatic responses only

Requires assistance to begin task

Requires prompt to begin task

Goal directed action



Please circle person's level of ability:

Walking

Automatic responses only

Requires assistance to begin task

Requires prompt to begin task

Goal directed action



Please circle person's level of ability:

Personal Care

Automatic responses only

Requires assistance to begin task

Requires prompt to begin task

Goal directed action



Please circle person's level of ability:

Activities

Automatic responses only

Requires assistance to begin task

Requires prompt to begin task

Goal directed action



6. Personal Preferences	Yes/No	Comments:
Food and drinks that the person likes	Yes No	
When and how the person likes to eat	Yes No	
Clothes the person likes to wear/how the person likes to look	Yes No	
Routines for Activities of Daily Living	Yes No	
Work-like activities that the person needs to do routinely	Yes No	
How the person relaxes	Yes No	
People, places or objects that the person feels attached to/are important/want with them	Yes No	
Spirituality	Yes No	
Cultural beliefs	Yes No	
Sexuality (Orientation, sexual needs and preferences)	Yes No	

7. Personality	Yes/No	Comments:
Comments or statements on personality dimensions	Yes No	

8. Life History	Yes/No	Comments:
Early Years		
Memories of family and friends	Yes No	

Memories of schooling and education	Yes No
(Interests, friends, teachers, achievements)	

Stories from early years	Yes No
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Middle Years

Memories of family and friends	Yes No
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Memories of things the person did	Yes No
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(Work, hobbies, holidays)

Stories from middle years	Yes No
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After Retirement

Memories of family and friends	Yes No
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Memories of things the person enjoyed	Yes No
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(Hobbies, travel etc)

Stories from after retirement	Yes No
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Now

Who and what I think about	Yes No
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(People close to me, proudest achievements, regrets, happiest memories)

Recent stories	Yes No
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Activities/hobbies I enjoy	Yes No
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9. Life at the moment	Yes/No	Comments:
Well-being/ill-being – how the person feels	Yes No	

Carer or significant other's satisfaction with the care (Any comments from carers)	Yes No	
Person with dementia's satisfaction with the care (Any comments from person with dementia)	Yes No	
Psychological needs (Comfort, occupation, attachment, identity, inclusion)	Yes No	

10. Future Wishes	Yes/No	Comments:
Plans for inability to communicate wishes in the future (Lifestyle preferences, treatments and support the person would/would not accept, list of people to consult regarding treatment and support decisions)	Yes No	
Mention of Advanced Directive or Living Will	Yes No	
Attorney's appointed (For property, welfare, Lasting Power of Attorney)	Yes No	

IDEA - proxy

Please think about the care your relative receives at the care home / ward and answer the following questions. Please choose only one answer for each question.

1. Do people here treat (name) with dignity?

Yes	Sometimes	No
1	2	3

2. Do people here treat (name) with respect?

Yes	Sometimes	No
1	2	3

3. Do people here treat (name) as an individual?

Yes	Sometimes	No
1	2	3

4. Do people here treat (name) as if he/she is important?

Yes	Sometimes	No
1	2	3

5. Is (Name) made to feel silly or stupid here?

Yes	Sometimes	No
1	2	3

6. Do people here involve (name) in decisions about his/her care?

Yes	Sometimes	No
1	2	3

7. Is (Name) ignored here?

Yes	Sometimes	No
1	2	3

8. Do people here talk down to (name)?

Yes	Sometimes	No
1	2	3

9. Do people look at (name) when they speak to him/her?

Yes	Sometimes	No
1	2	3

10. Do people here talk to (name) in a way he/she can understand?

Yes	Sometimes	No
1	2	3

11. Are (Name's) views ignored when decisions need to be made?

Yes	Sometimes	No
1	2	3

12. Do people here show an interest in (name)?

Yes	Sometimes	No
1	2	3

13. Do people here take the time to get to know (name)?

Yes	Sometimes	No
1	2	3

14. Do people here make assumptions about (name)?

Yes	Sometimes	No
1	2	3

15. Do people here help (name) to make decisions for himself / herself?

Yes	Sometimes	No
1	2	3

16. Is (Name) able to choose how he/she spends their time?

Yes	Sometimes	No
1	2	3

17. Does (Name) have to do what he/she is told here?

Yes	Sometimes	No
1	2	3

18. Do people here know who's important to (name) and respect this?

Yes	Sometimes	No
1	2	3

19. Are people (name) trusts involved in decisions about his/her care when he/she needs them to be?

Yes	Sometimes	No
1	2	3

20. Do people here give (name) the time to do things?

Yes	Sometimes	No
1	2	3

21. Do people here seem to understand (name's) problems?

Yes	Sometimes	No
1	2	3

22. Do people here take (name) seriously?

Yes	Sometimes	No
1	2	3

23. If (name) gets angry or upset do you think it will be held against him/her?

Yes	Sometimes	No
1	2	3

24. Is (Name) treated fairly here?

Yes	Sometimes	No
1	2	3

25. Do people here help (name) live as normal a life as possible?

Yes	Sometimes	No
1	2	3

26. Do people here respect (name's) choices in how he/she wants to live his/her life?

Yes	Sometimes	No
1	2	3

27. Do people treat (name) differently now?

Yes	Sometimes	No
1	2	3

28. Is (Name) supported to do lots of the things he/she used to do?

Yes	Sometimes	No
1	2	3

29. Does (Name) still have contact with the people who are important to him/her?

Yes	Sometimes	No
1	2	3

Interview Schedule

We are interested in asking you about how you make decisions in your day to day working life. There are no right or wrong answers and the information you give will not be shared with managers or supervisors. You are free to leave at any time. Do you have any questions?

Working within dementia care we are aware that you will regularly be in situations where you have to make complex clinical decisions about an individual's care. Could you tell us about some of the clinical situations that you find most challenging on a day to day basis?

I would now like to ask you about some specific situations you may encounter in your day to day working practice. Again there are no right or wrong answers we are just interested in your opinion.

Vignette 1

What would you do?

How would you come to this decision?

What would help you or support you in making this decision?

Vignette 2

What would you do?

How would you come to this decision?

What would help you or support you in making this decision?

Etc....

That is all the clinical situations we would like to ask you about. Do you think that the situations we have asked about reflect your day to day work?

Thank you for participating in this study. We will make you aware of any results from the work. Do you have any questions you would like to ask?

Vignettes set 1

Life History

Freedom of Expression – Anne is a married woman with a diagnosis of frontal temporal dementia. Since being admitted to the ward she has formed a close friendship with a male service user, John. John and Anne often sit together in the day room and have been seen holding hands and hugging each other. What would you do?

Neurological Impairment

Discrimination – Nadia has a diagnosis of Alzheimer's. Her son lives in Spain but has come over to visit her. 10 minutes before he is due to arrive you noticed that Nadia is soaked in urine. You encourage her to go for a wash and explain it is because her son is coming to visit. She refuses and does not seem to understand what you are telling her. What would you do?

Personality

Liberty – George has a diagnosis of Alzheimer's and has been on the ward for several weeks. His family report that he has always been an active man who has enjoyed the outdoors. It has been noticed that George spends long periods of time pacing around the ward. At times this irritates other service users. George can become tired after pacing and at times he has stumbled but never fallen. Because of this a member of staff needs to accompany him when he walking around the ward. What would you do?

Health

Degrading Treatment – Sheila was admitted to the dementia ward from the nursing home she lives in as they had noticed an increase in her levels of agitation. She recently had a fall whilst she was going to the toilet. Despite this she insists that she does not want someone to assist her and can go to the toilet on her own. What would you do?

Social Psychology

Peaceful enjoyment of possessions – Rajesh has always been interested in music and listening to it often calms him down. His family have brought him in a CD player and a selection of CDs. There has been an issue with another service user going into people's rooms and taking their personal possessions. Rajesh's family have asked whether his CDs will be safe. What would you do?

Vignettes set 2

Life History

Discrimination – Frank is an ex-boxer and despite his diagnosis of vascular dementia he is still extremely physically fit. It has been recorded that at times he has hit out at both staff and other service users on the ward. When this is discussed with his family at ward round they confide that he has a history of violence within the home and they do not want him to return home. What would you do?

Neurological Impairment

Liberty – Desmond has been admitted to the dementia ward on an informal basis. He is often observed rattling the front door and asking to go out. His family question this. They are told that all service users who are on the ward on an informal basis are given the code to the door. His family state that because of his memory problems he would be unable to retain this information. What would you do?

Personality

Freedom of expression – Ping is a 75 year old lady with a diagnosis of vascular dementia. She has been prescribed a variety of medications to help control multiple physical problems and also to help with her agitation. Every day at medication time Ping states that she has always been a fit and healthy woman and does not need to take any medication. She then refuses to take it. What would you do?

Health

Right to life – Norman has a diagnosis of Alzheimer's but also suffers with an undiagnosed medical condition resulting in urinary retention. The urinary retention requires the insertion of a catheter at the local acute hospital and some further investigations to diagnose the condition. The family have asked that whilst Norman is on the dementia ward could the staff accompany him to these appointments. When staff have attended with him in the past he has become very agitated and distressed and one occasion slid out of his wheelchair onto the floor. What would you do?

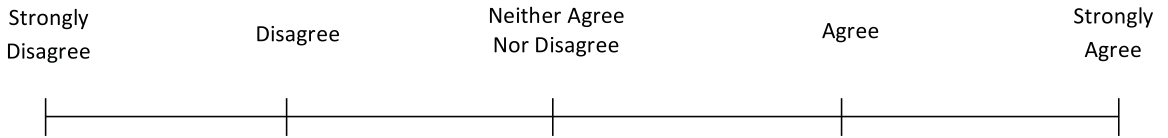
Social Psychology

Private family life – Joan has a diagnosis of Alzheimer's and has been becoming increasingly distressed on the ward. During the afternoon she becomes increasingly aggressive with both staff and other service users, eventually hitting another female service user. The decision is made to give Joan PRN medication and she then goes to sleep. When her family come to see her she has been asleep for about 30 minutes. What would you do?

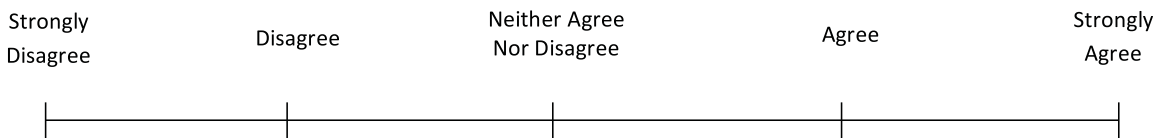
Attitudes Quiz

Please circle your answer to the following questions.

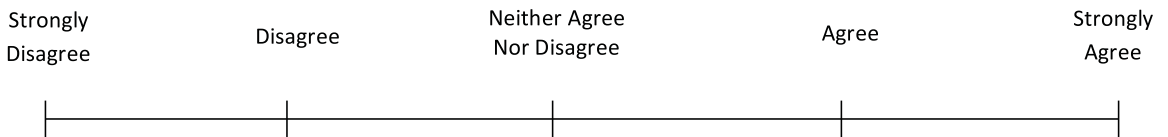
1. I feel I understand the idea of human rights.



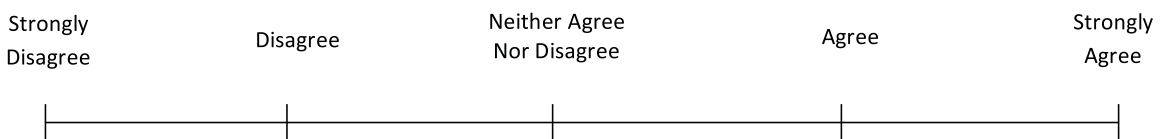
2. Human rights are important for everyone.



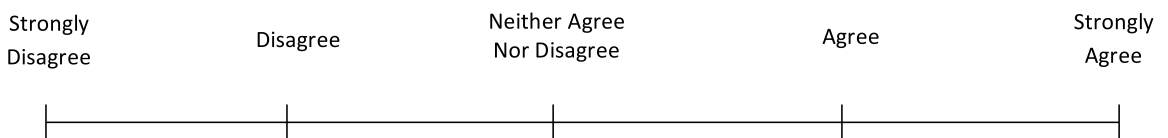
3. It is important to protect a person's human rights, regardless of who they are.



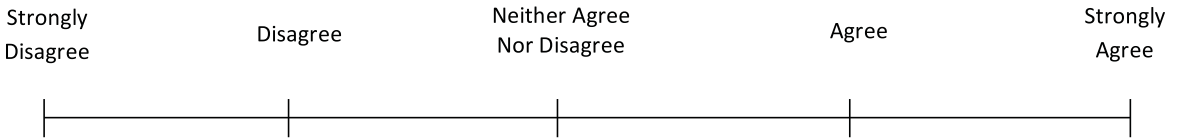
4. The idea of human rights is something I do not consider important as part of my own values, attitudes and beliefs.



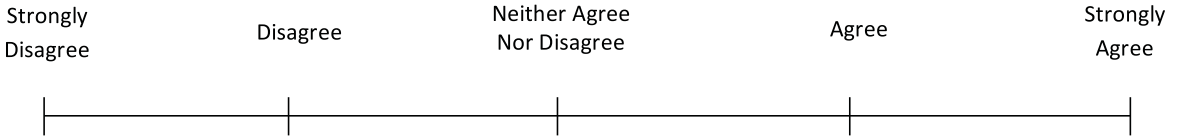
5. The idea of human rights fits well with my understanding of the core values, aims and objectives of the NHS.



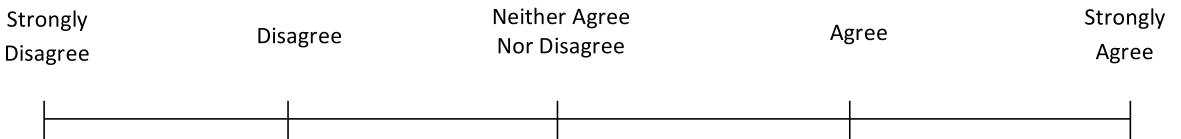
6. Human rights are not useful or relevant to my day-to-day work.



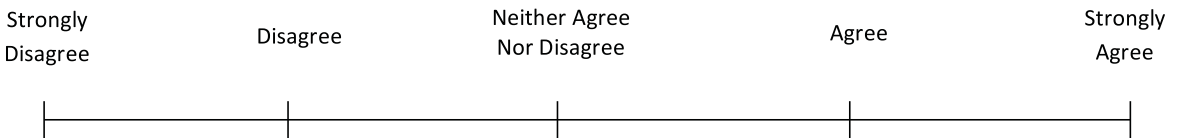
7. Human rights are about doing what is decent and fair.



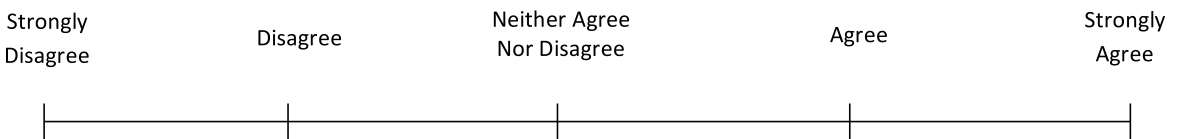
8. I feel that my own human rights are respected and I am treated well within my organisation.



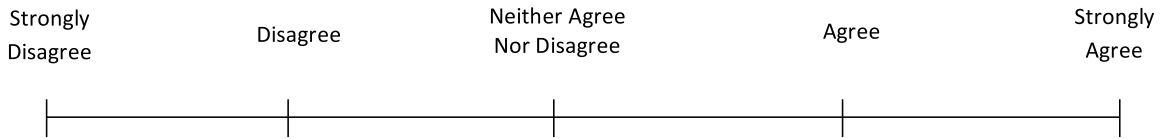
9. When people talk to me about human rights I feel pressured to work in a way I don't like.



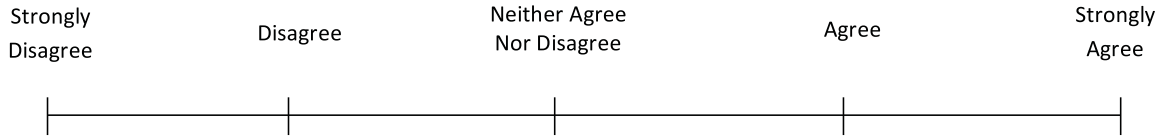
10. Positive change can happen at work using human rights values and approaches.



11. Other people in my team at work do not have a strong belief in human rights.



12. My family and friends have a strong belief in human rights.



Knowledge Quiz

Please circle one correct answer for each of the following questions

1. Human rights:

- a) Belong to certain groups at certain times
- b) Can be taken away from any of us
- c) Are claimed and cannot be taken away

2. In the United Kingdom who is protected by the Human Rights Act?

- a) Everyone who works for a government organisation (e.g. nurses, teachers and civil servants)
- b) Everyone who has the right to vote
- c) Everyone regardless of status
- d) Everyone who is a UK citizen

3. In which of the following circumstances do the NHS and its staff have a responsibility to act in relation to human rights?

- a) Preventing breaches of human rights; for example, intervening to protect one individual from the actions of another
- b) Informing individuals when their rights may be at risk - so they can make decisions to protect their own rights
- c) Responding to breaches of human rights, including investigating what has happened
- d) All of the above

4. The framework that gives the rights contained in the European Convention on Human Rights direct effect in UK law is:

- a) The Bill of Rights
- b) The UK constitution
- c) The Human Rights Act

5. FREDA stands for:

- a) Freedom, Respect, Equality, Diversity, Autonomy
- b) Fairness, Rights, Equality, Dignity, Autonomy
- c) Fairness, Respect, Equality, Dignity, Autonomy

6. Non-absolute rights can be interfered with if the action/decision is:

- a) In pursuit of a legitimate aim
- b) Lawful
- c) Necessary

- d) Proportionate
- e) All of the above
- f) Only b and d

7. Which one of the following rights is absolute?

- a) The right to respect for private and family life, home and correspondence
- b) The right to be free from inhuman or degrading treatment
- c) The right to freedom of expression
- d) The right to manifest one's religion or belief.

8. The right to respect for private life and family life, home and correspondence includes which of the following?

- a) Physical wellbeing
- b) Psychological wellbeing
- c) The right to a house
- d) Not having your post intercepted
- e) a, b and d
- f) a, b and c

9. When a person lacks the capacity to give informed consent to treatment Deprivation of Liberty Safeguards (DoLS) should be applied for:

- a) Whenever something is to be done to an individual which is outside of usual working practice
- b) As part of best practice, as soon as someone is admitted to a ward environment
- c) Whenever something is to be done to an individual which deprives them of their liberty.

10. Which of the following is not part of a human rights based approach:

- a) Putting human rights at the heart of policy and planning
- b) Empowering staff & service users
- c) Ensuring clear accountability
- d) Non-discrimination and attention to vulnerable groups
- e) Ensuring you always do what the service user wants
- f) Enabling meaningful involvement and participation of all key people

11. A proactive strategy is primarily a response that aims to minimise harm by acting:

- a) Before an event
- b) During an event
- c) After an event

12. Proportionality means the same as:

- a) Using the least restrictive strategy
- b) Using common custom and practice
- c) Doing what the person and their family want

13. Which of the following people's human rights might need to be taken into account when making decisions in a healthcare organisation?

- a) Service users
- b) Carers
- c) Staff
- d) The wider community
- e) All of the above