healthwatch

NHS Long Term Plan

Consultation Report

London Borough of Lambeth

what would you do?

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General Report

Introduction

Eighty-four (84) people from Lambeth completed the online questionnaire and responded to the questions pertaining to healthy life, managing and choosing support, independence as they grow older, and interaction with local NHS. Fifty respondents (50 or 60%) are between 25 and 64 years old and 7 (9%) are aged 18-24 (1) and over 65s (6). The rest (28) did not indicate their age.

Of the 84, 15 said they have disabilities and 13 said they also care for someone with long term conditions. In terms of ethnicity, 33% (28) are White British whilst 45% (38) are of different ethnicities.

The responses are summarised into two sections. Section 1 is discussion on questions pertaining to living a healthy life, managing and choosing health, independence as they get older, and interaction with local NHS.

Section 2 summarises the comments from 41 of the 84 who filled out the free text box in the questionnaire.

Section 1

1.1 Living a Healthy Life

Eighty per cent (80%) of the 84 respondents said that the most important thing to them is having access to information about health services. The two next most important things with 79% each are having access to help and treatment they need when they want it and having professionals that listen to them when they speak about their concerns. The fourth most important thing (70%) is having knowledge to help them do what they can to prevent ill health whilst the fifth most important aspect (69%) is for every interaction with health and care to count.

Respondents ranked the things that are most important to them to live a healthy life. Forty-four percent (44%) said that the number one thing is having access to services when they need it. This is followed by professionals that listen to them when they speak (21%); having the knowledge to help them do to prevent ill health (15%); easy access to information (12%), and (8%) is for every interaction with health and care services to count.

1.2 Managing and choosing support

Respondents responded to 8 questions related to manage and choose support. The first most important thing (65%) is ‘choosing the right support is a joint decision’. This is followed by ‘having time to consider their options and make choices that are right’ (61%) and the third most important thing is timely communications (60%). This resonated well with their replies to the question how they can manage and choose the support they need (Q8) to which 41% said they should be able to choose the right treatment; and second with 15% is about being offered care and support in other areas.

1.3 Independence as they get older

The most important of all aspects was being able to stay in own home for as long as it is safe to do so (81%). This is followed by wanting their family to feel supported at the end of life (79%). The third most important thing is having convenient ways for them to travel to health and care services (68%). When respondents were asked to rank the important things in helping them to be independent, 38% said *'I want my family and friends to have the knowledge to help and support me when needed'* is the first most important thing. This is followed by having the community as able to support them to live their life the way they want (26%) whilst 24% said that they want to be able to stay in their own home for as long as it is safe to do so.

1.4 Interaction with local NHS

The first three most important things people said about their interaction with local NHS are having absolute confidence that their personal data are managed securely (70%); any results are communicated to them quickly (52%); and that they can access services using phone or computer (48%).

32% ranked *'I can talk to my doctor or other professional wherever I am'* as the most important thing, followed by being able to book appointment online (14%) and that results are communicated to them quickly making best use of technology (14%).

It can be said that privacy and security of data is deemed as an important aspect of health care and one that people value most as they interact with their local NHS. They also want prompt communication of any results and can access services by phone or computer. Also, equally important are ease of booking appointment and relationship with the professional.

Section 2

This is the summary of the 41 comments people indicated in the free text boxes.

2.1 Holistic support for health and wellbeing

Some respondents said that there should be a wider societal view of health rather than focus on medication, illness, and disease. They said that they would benefit for being connected (not signposted) to a holistic lifestyle service to support in successfully making life changes.

Some also value physical exercises to stay well and help people with mental health issues. They would like to have access to places such as gyms and free physical activities as well as information on how they can lose weight or keep fit. They also find the connection between preventing diabetes and being physically active and that people should be encouraged and supported to access free physical exercises.

Quite a few suggested to support them in having greater awareness of the impact that certain foods or lifestyles can have on your health later on, from an early age (e.g. school); especially for the female population. It was said that there isn't enough education about menstruation and how diet and exercise can have a positive/negative impact on a female's health. Some said that not all families are comfortable talking about this topic at home, and so general awareness raising would help.

Some suggested better information at the start of life - starting as early as primary school level. This may include messages that are not too bland and basic (like, "sugar is always bad") but relevant and easily understood, for example, "diet of too much sugar puts you at risk of developing diabetes because of the strain you put on your insulin production".

Practical suggestions also included: having a walking companion for country walks, less pollution, and more preventative measures to stay healthy.

One respondent suggested that all professionals should be trained to support people with joint decision making and that statutory and voluntary sector work better together to provide the care, treatment, and support possible.

2.2 Booking appointment

People value having access to easy booking systems using various ways including computer, paper and telephone, and that appointments can be booked on different days and times, and can be booked in advanced. They want to access their doctors when they need to from places near to their residence. In addition, they said that they don't want to suffer long waiting for their appointments. Those who also have tests would appreciate discussing the results with the GP who referred them for tests. Some want to access blood test service in the nearest hospital instead of, for example, Gracefield Gardens in Streatham Lambeth, which is far from the person's residence.

2.3 Accessible information

Respondents said that information should be clear, easy to understand, and jargon-free. This includes more information on certain conditions which will be useful for the person to decide with the doctor about the treatment. Whilst some appreciate the new technology, hard copies are also welcome, and even preferred by some.

Accessing information also includes the facility to do online consultation with the GP or consultants. They said there should be a named person to talk to.

2.4 Accessible, timely services

Respondents want doctors to get it right the first time and shorter waiting time to see specialists. One respondent said she did not have good support for her mental health condition, which resulted to family stress. One said she has been waiting for 16-20 weeks for an assessment.

Also, on mental health, there were suggestions to have more investment in evidence-based talking therapies i.e. the ability to access CBT without waiting for months and to receive it for as long as needed within reason [time limits are fine, but these are currently too tight and inflexible].

The importance of faster access to GPs was also identified for good experience, the current wait time is over three weeks. The person feels pressured to take the first available appointment, even if it isn't convenient and has to take time off work.

It was suggested that alternative ways of improving mental and physical health, such as exercise, could be made more accessible through NHS contact for those who might not be able to access due to confidence, mobility, and finance.

They also said that experts should be in one building not trailing from place to place to see different doctors.

2.5 Professionals' knowledge

GPs are seen to have limited knowledge to advise and they often only google the condition. A few respondents said that they also need prompting so they will tell you more about your condition. If the patient does not know anything, the patient will not be well as the GPO is not proactive.

There is an expectation for GPs to know which service would best suit the person and the needs and be able to advise accordingly. According to some, they don't know about local services to appropriately enable choice. In addition, one shouldn't be offered multiple hospitals as choices, without being given the information about why you would want one over the other.

Health professionals are seen as experts in medical conditions but the person with the condition may know their individual circumstances better. Therefore, all options should be presented in a balanced manner.

One also said that local GP's don't know enough about other local services so offer unhelpful choices to patients and let the patient arbitrarily chose between different hospitals for their ongoing care. GP's can also be the gate keepers to secondary care. A good GP would mean you would always be presented with and advised on the best option. A bad GP will give you biased and unhelpful advice or uniformed choices. Lastly, some said that NHS professionals and carers must not talk down to patients.

2.6 Ability to stay at own property

One person said that she prefers to stay in her own property and to be able to look after herself for as long as possible but recognise that she may need support from the family and carers. Crucially would like to have some community based support such as nursing and social care support, which used to be available in the community but is now not easily available. She also wants home visits by GP and health workers.

Discussion on General Survey

It can be gleaned from the responses above that respondents want health to be approached in a holistic manner that includes preventative and early intervention measures, easy access to information and services, and enabling patients and family to live a healthy life.

First, they want easy access to information and services and for the services to be local or near their residence. They suggested the following: easily accessible information about services, including free of charge that they could access to keep fit; more guidance from doctors and other health professionals about choices; and upskilling GPs so that they can advise patients better.

Second, respondents see health professional as enablers both to the patient and to the family. They want professionals to be knowledgeable enough so that they can explain the condition to the patient and enable them to make choices about the service/s they need. They should also know about local services and be able to explain to patients.

Third, respondents would like to be given options on how to book their appointment – using paper, phone, email or online booking methods. They also want to have shorter waiting time for their appointments including assessment or receiving the service/s they need.

Specific Conditions report

Introduction

The experience of people with long term or specific conditions were gathered through an online survey and focus group discussions with people with Learning Disability/Autism and people with Mental Health conditions.

Twenty-six (26) people with specific conditions responded to the online questionnaire. Of the 26, four (4) have mental health conditions and 12 have Learning Disability/Autism – 62% of the total number of respondents. Other conditions include: cancer (1), heart and lung disease (2), other long-term conditions not specified (7). Of the 26, 15 (58%) have two or more conditions.

Learning Disability and Mental Health are the two conditions being prioritised by Our Healthier South East London (OHSEL). It appears that these two conditions had the highest number of respondents in the online survey.

We conducted four focus group discussions attended by 43 people. Two focus group discussions on mental health were attended by 17 service users and 3 carers. The two FGD with people with Learning Disabilities were attended by 15 people with LD and 8 parents/carers.

This sub-section presents the outputs from the online survey (Section 1) and the four FGDs (Section 2).

Section 1 – Online Survey (Specific conditions)

Twenty-six (26) people with long term conditions responded to the online survey. The profile of the respondents shows that 13 or 50% are 35-44 years old (6) and 55-64 years old (7). The other age brackets had 2 respondents each. This indicates that half of those with long term conditions are of working age group.

In terms of ethnicity, 10 or 38% are White British and 62% or 16 people are from different ethnic backgrounds. This reflects the ethnic diversity in Lambeth.

1.1 Overall experience of care and support

This sub-section presents the experience of people with specific and long-term conditions on getting the support they need, access to specialists, and waiting time.

Fifteen (15) or 58% said that the support they got did not meet their needs. Only 5 said that the support met their needs whilst 6 said the support was ‘somewhat’. The experience of support coincides with the overall experience of getting help which is negative and very negative according to 12 people (50%). Only six (6) said that the service is average and seven (7) had positive experience.

Twenty (20) or 77% said they were referred to a specialist but that the waiting time between the initial appointment and seeing the specialist for 45% (9) was either very slow or slow. Even for those with multiple conditions, 9 (69%) said that it made it even harder to get the support they need whilst 3 said that having more than one condition made no difference in getting the support.

Waiting for the initial assessment/diagnosis was slow or very slow for 12 (46%) and ‘OK’ for 10 (38%). Only one person said that their experience was ‘fast’.

In terms of accessing ongoing support after the diagnosis, 13 (61%) of 21 replies said that it was either difficult or very difficult; 6 said it was OK and 4 said it was very easy and easy. Of those who got the services, 11 (46%) said the support did not meet their expectations compared to 8 (33%) who said the support met their expectations. The communication was also found untimely by 11 (46%) compared to 7 (29%) who said that the communication was timely.

1.2 What is most important to people with long term needs

The 26 respondents ranked the most important things to them at each stage of their care. The first stage is ‘when first seeking help’ and 16 (62%) said that seeing any medically appropriate health professional who is free immediately’ is the most important thing. The priority changes after the initial stage in that 46% (12) ranked ‘seeing health professional you normally see but you may have to wait’ as their first priority. This is the same with the other last two stages (‘during initial treatment’ and ‘during long term support’) of which 13 and 11 indicated they want to see the same professional even if they have to wait.

It can be gleaned from the above that people with long term conditions prefer to see the professional they are most familiar with and who already know their conditions.

Section 2 – Focus Group Discussions

2.1 Learning Disability

The LD participants were shown pictures of health services in primary and secondary settings, in the community, things that relate to health like smoking, alcohol, diet (five a day), exercise; clock (to symbolise time); breast screening; different ways to communicate (letter, email, phone) and modes of travel; and photos of friends holding hands and are happy. As people of LD may not have concept of time duration and often would use long or short, the facilitator clarified what long and short are. We used examples such as: walking up to five bus stops could be approximately 5 to10 minutes with medium-paced walk and traveling to for example Brixton from Streatham could be 30 minutes. Some said 30 minutes is short and more than that would be considered long. Hence, when people discussed long waiting time, we go back to 10 to 30 minutes as short; and more than that is considered long waiting time.

Some participants with severe learning disability could only say yes or no and could not write – and so their carers spoke for them.

Key themes identified:

2.1.1 Most people with Learning Disability cannot book health appointments and need support to do so

More than half the 20 participants said that they cannot book over the phone or through any means and this must be done by their family/relative or carer. They also said that they receive letter reminding them of their appointments. They said they attend appointments. When asked why, one said *“You’ve got to, it is important’*.

One participant who can book appointments on her own said that whenever she needs to see her GP, she would call him, but the receptionist tells her it would take up to three weeks to see a GP. She would just go to walk in clinics. However, she also said that it takes up to an hour to wait.

One participant said that sometimes he goes to the doctor and sometimes the doctor comes to his house. He is also given the opportunity to choose hospital and said he never liked King’s College Hospital.

2.1.2 They understand the importance of prevention and staying well

All people with LD value the importance of physical health and said that they can maintain physical health by eating five a day, exercising, not smoking and not drinking alcohol. They said that smoking and drinking are bad for health. One said that drinking eight glasses of water is good and that she does this and makes her feel good. When they mentioned five-a-day – the facilitator asked what it means. One participant said that one must eat five types of fruits and vegetables in one day. Another participant said that it should also include protein and vitamins to make them healthy.

They also talked of friendship and how having friends will be good to encourage people in attending appointments and crossing the road (the latter is where they also talked of safety on the street and how having a friend is helpful). Two of them said that they have friends who remind them of their appointments.

One participant spoke about the need to keep fit and being active. He also spoke about the need for healthy diet, physical exercises, lifelong learning, swimming and painting.

People with MH conditions also said they already access a range of universal services such as the gym, dance classes, walking group, swimming, amongst other things. However, some said that those are not the activities they would like to access and struggle to find alternative activities.

Parents of children with LD and autism said that they value good physical health for their children, but often physical exercise is limited. Interestingly, between the two participants, there is disparity in information being accessed.

When asked how this disparity in access to information can be addressed, they said that parents should be empowered to ask questions and to have the confidence to navigate the system. Where this is not possible, for example for parents who themselves have autism or learning disability, information should be readily available and accessible.

2.1.4 The experience of accessing primary and secondary care varies

Experience of GP

Overall, for people with mental health conditions, GPs are seen in a positive light but there was also an assumption from the majority of the participants that doctors only do medication. Two however had different experience in that they said their GPs had been more holistic.

Some said that they had difficulty accessing their GPs and felt that people with mental health conditions should be given priority.

Carers also have similar view of the GP service saying that they don’t understand the carers’ situation. Those who have sought help from their GP assumed that they can cope but, in reality, some carers are also suffering from depression and also in need of counselling. They were expecting their GP to be more supportive and knowledgeable of other services they can be signposted to.

Carers also talked of their difficulty caring for the person with mental health problems when they were discharged from hospitals, saying they did not get help and no one came to assess their needs.

People with Learning Disabilities remembered their last visit to their GP which according to them was ok. However, some also shared that they did not like it. For example, one said that the doctor did not ask enough question about the health problem she wanted to discuss. Instead he was talking about how and why he should lose weight. One person appreciates that it is easy for people with LD to hear the nurse calling their name and to see their name on the screen as they wait for their turn.

Community Mental Health Teams

Some people with mental health conditions reported a fairly positive experience of their Community Mental Health Teams (CMHTs) and care coordinators but the majority were in agreement that access to specialist services is very difficult. They said that they have to wait for a long time before they can access any support.

Talking Therapies

People with mental health conditions said that talking therapies are *‘useless’* as the waiting time is very long and being in the waiting list for a long time even causes more stress. However, some carers had different experience of talking therapies, saying that they found them useful.

Hospitals

Similarly, some carers of people with LD also found having dental and hearing check-ups on different days stressful. One carer had to arrange for her daughter's different appointments to be held in one day as she gets anxious going to hospitals for check-ups.

It was suggested that the patients with LD should receive the same opportunity and be offered the chance to have different checks in one day/appointment. They said that professionals should coordinate the services because people with LD will be unable to ask for it.

One participant remembers her experience bringing her daughter to blood test and they were sent to Dulwich Hospital. They found it hard to locate the blood test unit. They all agreed it is important to have good signages - colour-coded like underground trains and with big letters. Those who have used KCH said everyone even the cleaner can help in giving directions because they are all trained.

3.2 Professionals have low awareness on disability

People with LD felt that the awareness of hospital staff of disability is low. One carer shared her experience how she accompanies her sister with down syndrome to A&E and the sister was transferred to a wrong ward because the nurse that assessed her sister did not have the skills to identify a Down's Syndrome patient. Another said he was wrongly diagnosed at Guy's Hospital with Epilepsy for twenty years and how he was subsequently told at St George's Hospital that what he has is not Epilepsy but emotional fit.

It was suggested that there should be a system that could easily identify patients where ever they present themselves to avoid confusion and misunderstanding. When asked what can be used to flag learning disability, they suggested to use purple star ++ and purple star +.

Parents of young people with LD said that the doctor dismissed the symptoms of autism and instead prescribed him paracetamol. She said that doctors should be trained in spotting autism or even just to consider what parents are telling them and not be dismissive of their ideas.

Another parent talked about her child who tends to be violent some of the times. She was brought to Evelina Hospital for a blood test, but he was unfamiliar with the new doctor. The health professional lied to the child saying no blood would be taken and they would just check his muscles. The other parent had similar experience of her child to be restrained so they could get blood. The parent told them not to restrain but to model blood taking and use her to show how it is done.

Both parents said that all health professionals should be trained on how to deal with children with autism and learning disability. They should also work with parents to understand the needs of the child.

3.3 People with MH conditions don't access information about services

People with MH conditions said that they receive limited information and do rely heavily on service providers like Southside Rehabilitation Association (a voluntary sector group) to help them access support. They also don't access information and signposting resources. They suggested that there should be a more personalised approach where things are included in their care plan. Some however said that there is too much information on a lot of things and that this does not work for them. They would prefer that the information is tailored to their need because not everyone wants the same things.

They suggested that information should be short and written on a one-page paper with information on how to access them. They also mentioned the libraries as a good place to do things such as reading the paper, having access to the internet, and to find out what things are happening. Carers also suggested that GP should be the point of contact and there should be information about services they can access for themselves and for the individual they care for at GP surgeries.

It has become apparent that very few are aware of crises services in Lambeth. Those needing pre-crisis support who said they were about to have relapses could not find services welcoming enough with people who understand where they are coming from. They are also unaware of the Home Treatment Team and so the tendency is for them to wait for their Community Mental Health Team or to go to the A and E. Only one person knew about Sanctuary at Mosaic.

3.4 Mind and Body are treated separately

People with mental health conditions said that mind and body are not treated together. They also commented that there is too much focus on medication by nurses, psychiatrists and GPs. They find the voluntary sector group to be better at encouraging them to do something different. Some also had good words about their key workers from the housing department who exert effort to get to know them and help with other things. However, two participants had good experience of their GPs, saying that they take time to explain to them about healthy eating and side effects of medication. Interestingly, most of them said they did not expect their GP to do the same.

Parents of children and young people with LD/autism said that introducing more play time and more physical activities in school is beneficial. She said that it does enable her child to have a pleasant sleep. Alongside physical exercise, they value some therapies like mindfulness. One mum who herself had anxiety and post-natal mental health issues said that mindfulness worked for her. Another parent talked about her child who is very violent, saying that therapy talking has helped her a lot.

In addition, parents of children with LD/Autism said that therapies can be offered in different ways such as face to face or online. One mother said that she wants online therapies where she can dip and out depending on her availability.

3.5 People’s understanding of the value of screening

Three females said that they attended their breast screening because it is important. They received the letter from their GP and they called them to set the appointment. The carer looking after her daughter with LD said that her daughter did not want to attend the breast screening because she did not know if it was a female or male doctor. They all agreed that patients with LD should be told the sex of the health professional performing the screening.

Everyone said they attended the annual health check and some have health plan. They said it is important to know if they have diabetes or heart disease. However, all the females did not enjoy the experience of the breast screening, and one did not like pricking of her finger for blood. They said that they should be informed of what to expect before they go to the hospital or GP. They added that leaflet with flow chart of stages or steps with pictures of what the screening is about to happen at the appointment should be sent to them.

One participant with LD and cancer said that he was advised by the doctor to stop smoking and drinking after he was diagnosed with cancer. He said that he actually stopped smoking and drinking and his cancer went into remission and eventually he was cured.

However, it was also said how people with learning disability are not adequately given appointment for cancer screening.

3.6 Some aspects on health inequalities that prevents and contribute to living healthily

The participants mentioned different ways to help them live well and stay healthy which can be categorised into access to resources/services and tackling inequalities.

First – they suggested that they need time to relax and to be supported by other people they can talk to. They also said that access to services like talking therapies should be quicker in addition to having other alternatives to talking therapies such as peer mentors and befrienders.

In terms of tackling health inequalities, they talked about factors they associate with mental health including money, benefits, housing, employment and having a meaningful life. They said that they don't have enough money to live on, even to meet the very basic. This then contribute to difficulty of staying well because they can't do anything. They also said that since they were out of employment for a long time, they would find it hard to be back into it. They suggested paid sheltered employment, mentioning SRA as a positive example. For most of them, having something meaningful to do is important and it is not only about work.

Having decent housing was mentioned to be hugely important to one's wellbeing. They said that housing landlords are not very supportive. One had worries about potential eviction which had caused her distress.

Carers said that they try to be fit and healthy but prefer not to be dependent on services. They said that they should be enabled to make their own arrangements, e.g. for respite care.

Discussion on specific conditions online survey and focus group discussions

The survey responses from 26 people with certain long-term conditions showed that their experience of support and care has been generally negative. 58% said that the services they received did not meet their expectations. This is despite of spending long time to wait for the service. The majority (45%) said that services are slow compared to only 38% of those with 'average' experience. In fact, only one person said that the service is fast.

Once they receive their diagnosis, the experience of ongoing support is also very unsatisfactory as 61% said that it was very difficult to receive ongoing support. Of those who eventually received ongoing support, 46% said it did not meet their expectations.

The focus group discussions provided an opportunity to explore further people's experiences of support.

It has become apparent that people with Learning Disability and mental health conditions understand the importance of being healthy and most of them know how to look after themselves. They also understand the importance of health screening especially the annual health checks. They understand the importance of diet, exercise, and quitting smoking and alcohol.

They had varied experiences of health professionals and secondary care, but it is important to highlight two things: first, the lack of awareness of some health professionals on disability that leads to unsatisfactory experience of people with LD; and second, the need to improve information and communication both in the settings and information about the checks they will be having. Communication also includes easy access to places by making signs clearer and bigger, awareness raising and training for all hospital personnel to spot people with LD and provide the necessary assistance to patients with LD and devise a system to flag up certain disabilities so that patients receive the appropriate care.

Coordination of services was also highlighted as an important aspect of better experience of health services. Whilst carers could make requests, people with LD themselves may not be able to do so. People with mental health conditions also said that there is lack of coordinated support. According to them, it takes weeks, even months for the coordinator to call them.

Parents of young people with LD said that the lack of awareness and skills amongst health professionals to support children with LD/autism, and second, lack of consistent information sharing about services and support to families affect family's access to services. To address these, the health workforce should be skilled up. In addition, parents should also be empowered/enabled to ask questions, and this should be encouraged by health professionals, and not be dismissed. In terms access to information - there should be consistent information sharing/giving to all parents so that all will have equal opportunity to access services. This can be done in a variety of ways including online, in paper copy (e.g. leaflets), and face to face (e.g. coffee mornings, networking events).

Conclusion

It can be gleaned from the results of the general and specific conditions survey that people with certain conditions have less satisfactory experience of health services. The outputs from the four focus group discussions also showed that whilst people understand the value of health, their experience of care and support considerably vary.

The same issues come up over and over again, including: difficulty in accessing information about services and access to services; lack of awareness of health professionals about certain disabilities; very long waiting time. People with more than one condition also find that accessing support is difficult.

First, primary care professionals are seen as the 'gatekeepers' to services and are expected to have understanding of the patients' conditions, the services available, and be able to guide the patients as they make decisions about care and support. Carers of people with LD and mental health conditions also expect them to inform them of the support they can access in the community.

Second, there is a need to upskill GPs and other health professionals on a number of topics. Some responses show that not all GPs know about the health condition of the patient and they rely on the internet. There were also comments on how they only attend to 'medical concerns' instead of looking at health holistically. It was suggested that they should be more aware of patients' conditions, so they can advise and guide them. Health professionals also need to increase awareness about disabilities, so they can support them better.

Third, people can benefit from different options to book appointments – via phone, email, online, and letters.

Fourth, there was a suggestion to approach health from the wider perspective and not only about medication. There were suggestions to offer preventative and early intervention services, including those that will address both physical health and mental health (i.e. Mind and Body).