

Personalised Food: the role of patient organisations as emergent critical change agents in the food system

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Abstract

Although concerns about health are a major driver behind the urban food movement, these concerns are mainly based on general notions of public health: eat more vegetables and fruits, less sugar, fat, salt, meat and carbohydrates, and more physical exercise. These notions lead to a diversity of programs and projects on food education, allotment gardens in cities, new fresh food hubs, markets and other innovative short supply chains, up until the agro-ecological (re-)design of urban neighbourhoods with a strong emphasis on food, LED-based growth of food in empty office buildings etcetera.

Paradoxically, those who are confronted most intensely with health, the patients, are virtually absent from the debate and praxis. Until recently. Of late, a patients movement on food is emerging in The Netherlands, campaigning for personalised food for individual health. Informal debate among patients is very often geared around food and new food regimes, as one of the main loci of control over their own process of recovery of health, or prevention from getting sick again. Recently, this informal process is getting louder, led by militant NGO's like Inspire2Live and VSOP. Their longing for food and food regimes that fit with their highly individual biomedical conditions, is now being picked up by the horticultural sector. The patients' perspectives and ambitions seem to coin a new and maybe promising avenue for change in the food system in general.

This paper aims to assess the patient's claims to good food and the role they can play in the development of sustainable food systems. It draws on an appraisal of the business potential of Personalised Food, carried out between January and July 2014, which was commissioned by the Amsterdam Economic Board and the Dutch province of Flevoland and in which patient organisations play a major role. The appraisal was based on qualitative in-depth interviews with key stakeholders, several multistakeholder innovation workshops, an online questionnaire on Personalised Food and deskresearch.

The paper shows the emergence of a polarity: Common Food for Public Health, and Individualised Food for Individual Health. Between these poles, a whole array of Personalised Food Systems is cristallizing. These PFS's have all unique combinations of varied actors in the triangle formed by a) agri- and horticulture, b) biomedical care and research, and c) patients and healthy citizens. They all demand and create unique production, logistic, care, maintenance, spatial and consumption concepts. Hence, the polarity between Common Food and Individualised Food also emerges as a promising analytical framework. The paper concludes that patients striving for Personalised Food may indeed play a pivotal role in a move towards a more sustainable food system. Yet, their potential goes along with some major questions and paradoxes. The paper ends with a request to the international food community to investigate and test these questions.

1. Introduction

Although concerns about health are a major driver behind the urban food movement, these concerns are mainly based on general notions of public health: eat more vegetables and fruits, less sugar, fat, salt, meat and carbohydrates, and more physical exercise. These notions lead to a diversity of programs and projects on food education, allotment gardens in cities, new fresh food hubs, markets and other innovative short supply chains, up until the agro-ecological (re-)design of urban neighbourhoods with a strong emphasis on food, LED-based growth of food in empty office buildings etcetera. Paradoxically, those who are confronted most intensely with health, the patients, are virtually absent from the debate and praxis. Until recently. Of late, a patients movement on food is emerging in The Netherlands, campaigning for personalised food for individual health. Informal debate among patients is very often geared around food and new food regimes, as one of the main loci of control over their own process of recovery of health, or prevention from getting sick again. Recently, this informal process is getting louder, led by militant Dutch patient NGO's like Inspire2Live and VSOP. Their longing for food and food regimes that fit with their highly individual biomedical conditions, is currently being picked up by the horticultural sector. The patients' perspectives and ambitions seem to coin a new and maybe promising avenue for change in the food system in general.

Patients are also virtually absent in theoretical framings around food and food system change. The new food geography, as presented by Wiskerke (2009) and Wiskerke and Viljoen (2012), defines an axis of the revaluation of public food procurement (food as purchased by governmental bodies, hospitals, schools etcetera), an axis of new short producer-consumer food chains (Community Supported Agriculture, farm shops, box schemes, organic and 'quality' products, etcetera) and an axis of urban food strategies (the active role of cities and metropolitan areas as food policy makers). Although patients might benefit from new food procurement strategies of hospitals – and indeed some hopeful Dutch examples are being developed (e.g. Maartenskliniek in the city of Nijmegen, and a new coalition between farmers and care institutions in the province of Brabant) – their specific role and ambitions hardly seem to play a role. Patients' claims and strategies to good foods seem not be covered either in the abundant literature on Alternative Food Networks (Maye, 2013).

This paper aims to address this void, and to assess the patient's claims to good food and the role they can play in the development of sustainable food systems. This is a first attempt, based on first outcomes of qualitative survey with selected stakeholders in the first half of 2014, in the context of an appraisal of the business potential of Personalised Food. The paper first outlines the context and methodology of this appraisal. It then

assesses the claims of patients to food that fits their needs. Next, it addresses the upcoming dichotomy between Personalised Food (PF) and Common Food (CF). Then, it outlines the challenge Personalised Food poses to the horticultural sector. The paper ends with a series of questions and a request for (international) collaboration.

2. The context and methodology of the appraisal on Personalised Food

Context

The appraisal of the business potential of Personalised Food, carried out between January and July 2014, was commissioned by the Amsterdam Economic Board / Amsterdam Chamber of Commerce, the province of Flevoland and the Centre of Expertise Greenports¹. On board of the steering committee also figured Inspire2Live, an NGO dedicated to converting cancer into a chronic disease by 2021, and run by patients². Inspire2Live played an important role in the conception of the appraisal.

The appraisal was born out of three urgencies. The first one was the perceived public anxiety of patients and citizens to feed themselves with food that really contributes to their health. Currently, an enormous body of food 'self-help' books is available in the stores; food, and especially what-food-for-what-health issue, is a hot topic in many public debates. About half of the Dutch cancer patients (about 100.000 annually) experiment with food. The crucial point Inspire2Live alleges is that general dietary advice gives a sense of direction, but does not provide satisfactory results in individual cases, nor is it helpful to understand why, e.g., some get fat eating cheese, while others don't.

The second urgency refers to the Dutch horticultural sector, which is in need of new economic perspectives. Market positions based mainly on production efficiency and scale are under pressure through global competition. The sector yearns for new 'breakthrough' themes that provide an appealing economic perspective. The third lead towards the appraisal was constituted by recent biomedical findings that suggest that it is indeed possible to define an individual match between a human and food. These results were made public by Prof. Hans Westerhoff³, and refer to the worldwide academic consensus on the 'metabolic map' (Thiele et al, 2013). This metabolic map

¹ The Centre of Expertise Greenports is a collaborative funding structure of Universities of Applied Sciences in the realm of food and agriculture in the Netherlands. It aims to conduct applied research upon request of businesses and other market actors, and should always generate input for the actualization and development of new curricula.

² The full mission of inspire2Live is: "Inspire2Live is an international Patient Advocates organization that inspires people (patients, clinicians and researchers), without limitations, to work together to get cancer under control by 2021 and to lead happy and healthy lives in harmony with cancer." (www.inspire2live.org)

³ Synthetic Systems Biology, Swammerdam institute for Life Sciences, UvA Amsterdam; Molecular Cell Physiology, NISB VU Amsterdam, Manchester Centre for Integrative Systems Biology, UK

establishes the approximately 7000 biochemical pathways that an individual develops based on his or her DNA code. Little variations in these maps provide important clues why some people should do better eating food of a certain type, while others would benefit from other types of food.

The interest of the Province of Flevoland in the appraisal was further enhanced by the fact that the Flevoland city of Almere will host, in 2022, the World Horticultural Exhibition. The 'Floriade 2022', as it is called, is meant to be a global showcase of the state of the art of the chosen central motto 'greening the city', with as leading themes 'feeding, greening, energizing and healthying the city'. Almere forms part of the Amsterdam Metropolitan Area. This area includes major horticultural centers, the Aalsmeer auction, and is home of a series of biomedical research and health care facilities of international reputation.

The goal of the project was defined as the identification of successful matches between the recent biomedical findings on the metabolic map, plant compounds, agricultural products, food and patient organisations. This successful match was understood as the emergence of business coalitions on Personalised Food. A business coalition was defined as a network of actors that form a logic connection between a disease, a patient organization, plant compounds, biomedical analysis, horticultural products and food, and that has the intention to develop a business model.

Methodology

The appraisal was carried out by the chair of Eco-effective entrepreneurship in urban environments at CAH Vilentum Almere University of Applied Science, with the logistic and network aid of the Development Agency of the Province of Flevoland (OMFL). It comprised of a series of over 30 in-depth qualitative interviews with key stakeholders from the horticultural and biomedical sector and patients, several multistakeholder innovation workshops, a questionnaire on Personalised Food, a brainstorm with patient organisations and desk research. The focus and scope of the research was supervised by a steering committee that was staffed by representatives of the funding organisations, the Dutch Knowledge Centre of Plant Compounds, a private research centre on biomedical and plant issues (Fytagoras), the Dutch Central Veterinary Service, the project lead of the Green Health Consortium (a collaborative network of a series of Dutch universities of applied science and Small and Medium Enterprises geared towards validating the medical potential of promising plants and cropping techniques), the University of Amsterdam/VU (Prof. Westerhoff) and Inspire2Live.

The bulk of the interviews were carried out between February and May, culminating in a big multistakeholder event that gathered the horticultural industry, biomedical and plant scientists, patient representatives of different organisations, teachers and students from various institutions and policy makers of municipal, regional and national level. This big 'Innovation Arena', as it was labeled, was followed by 2 in-depth workshops on potential

business coalitions, and a brainstorm exclusively with patients and patient groups. Between early April and June, an online questionnaire was set out to test the interest among patients, (semi-)professional sportsmen and 'normal' citizens (meaning not dealing with a severe disorder nor practicing sports at (semi-)professional level). The questionnaire yielded 453 respondents: 64% were patients, 16% were (semi-)professional sportsmen and 20 % were 'normal' citizens.

Overall, the project drew tremendous interest, most tangible at the Innovation Arena (100+ participants) and in the online questionnaire on Personalised Food. This paper is not meant to outline in detail the flow and outcomes of the appraisal, nor to discuss the emergence of new business coalitions. The paper instead aims to highlight the issues related to the role of patients and patient organization in relation to change of the agro food system. The full project outcomes and recommendations are documented and available (Remmers, 2014).

3. Patients' claims to food

A severe illness bumps a patient often into a situation of dependency and uncertainty. Food is one of the major issues that enable patients to contribute in a most tangible and daily way, to their health. Patients exchange abundantly tips for recipes, cooking advice, promising health supporting food, sources of reliable information, good doctors and medical advice. A 2004 assessment of the use of food supplements among breast cancer patients reveals that about 50 % resort to these supplement when faced with the diagnosis, and about half of them continue to use these supplements after the treatments (Meijer et al, 2004). The questionnaire on Personalised Food indicates that over 70 % of patients engage in home-experiments with food (Meijer, Wel and Remmers, 2014). Over half of them say it helps. Over 80% of the total questionnaire population (including also sportsmen and normal citizens) is interested in Personalised Food, and considers it important that it becomes available. About 75% is prepared to donate DNA for screening in order to foster research and development, and to generate a tailor made dietary advice. Patients even score significantly higher.

Patients, especially chronic patients, are at the same time desperate and stubborn and do undertake great effort to gain food advice that fits their needs, and, according to their own claims, achieve more often than not good results without support of the regular medical sector (quotes from the questionnaire):

“I suffered from muscle dystrophy. According to the doctor, my leg had to be amputated and I had to spend the rest of my life in a wheelchair. I refused and started experimenting with food. Now, 7 years later: I walk, sport and ride a horse.

Nobody notices any difference – but at closer look you'll see that one leg is a bit slimmer than the other. If I had listened to my doctor, I would have missed my leg. His reaction: spontaneous healing. Food couldn't have played any role in this... “

“After own research I now created a food routine that yields more results that I had ever hoped for. Especially the attacks of migraine, that I used to have about 3 a month for over 23 years, have dropped to 2 over the last 6 months! And this while my 'headache doctor', after extensive treatments, concluded I had untreatable migraine... It also improved my skin, the warts caused by my migraine medication disappeared, my cycle normalised (from 25-30 days to exactly 28 days) AND I finally gained weighed to healthy levels, something that diet food and other dietary prescriptions by my dietician, did not achieve...’

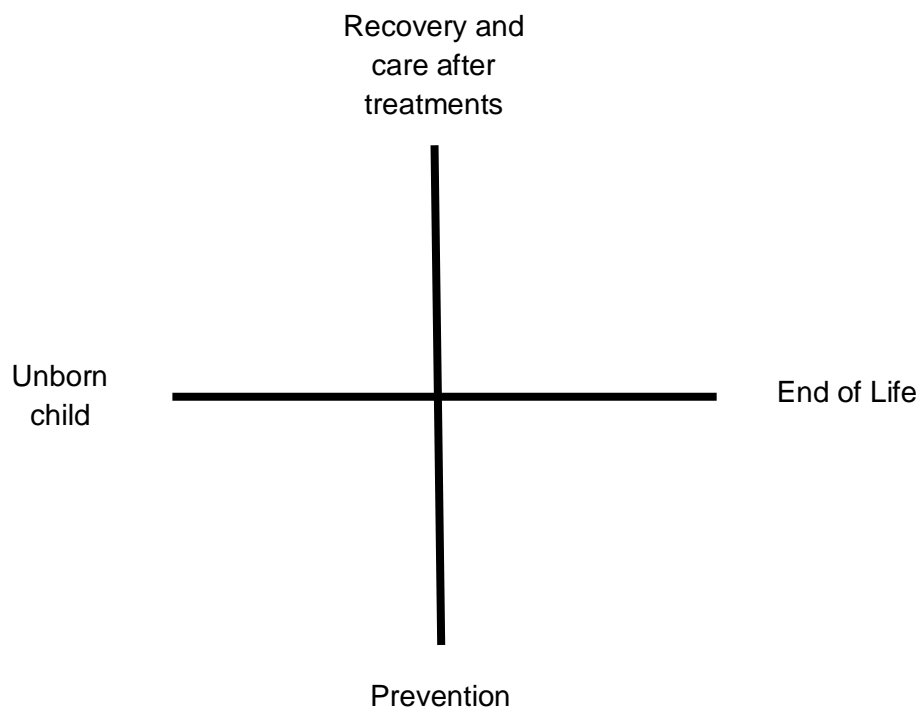
“Thanks to Ayurveda I have been able to overcome my auto-immune disease 10 years ago’.

The patients interest and dedication to food contrast quite strongly with the fact that there seems to be hardly any coordinated effort to generate a common patients perspective on food. Most patient's organisations deal with food independently. In 2013, a first attempt to generate a common agenda was formulated in the context of a project born out of the collaboration between two EU patient groups, namely the European Patient's Forum (EPF) and the European Genetic Alliance Network (EGAN). These groups joined forces with the European Nutrition for Health Alliance (ENHA), a multistakeholder group involving dieticians, doctors, food and pharma industry, working especially on a screening process for malnutrition (Gill'ard, Green and Smit, 2013). Their agenda gathered views of 8 different patient organisations throughout Europe, and is called 'patients perspectives on nutrition'. The agenda includes several recommendations. The focus is on nutrition, not so much on (fresh) food, and pays predominantly attention to (functional) food for assisting recovery, and little to food for prevention of getting sick at all. Using this agenda as a point of reference, a brainstorm was conducted in the course of the Personalised Food project in June 2014. The brainstorm led to the formulation of a series of key issues and recommendations on food and health, summarized here as follows (Remmers et al, 2014):

1. Actors in the health and food sector should collaborate as to empower food to become an acknowledged individualised medical prevention and intervention strategy, tuned to the stage in the treatment process and the phase of life one is in (see figure 1).
2. Improve early diagnostic methods, as to be able to design an adequate food strategy as quickly as possible, and to this purpose use DNA analyses, if possible at birth.

3. Monitor and systematize the experience based knowledge born out of the food experiments of patients and citizens
4. Take serious and validate alternative visions on food and health from other health traditions, e.g. Ayurveda
5. Food is not a single but a multiple drug. Food research should focus on the synergistic health effects of food
6. Healthy food is generated by a healthy food system. Actors should focus on creating a healing environment in all dimensions: natural cropping methods, healthy food offerings where groups are vulnerable and easily seduced (schools, sport canteens etc.), a green and inspiring built environment etc.
7. Make healthy food attractive and tasty. Food is not only medicine, it also enjoyment and social contact. Don't medicalise food.

Figure 1. Food should fit both the stage of treatment and the life phase one is in.



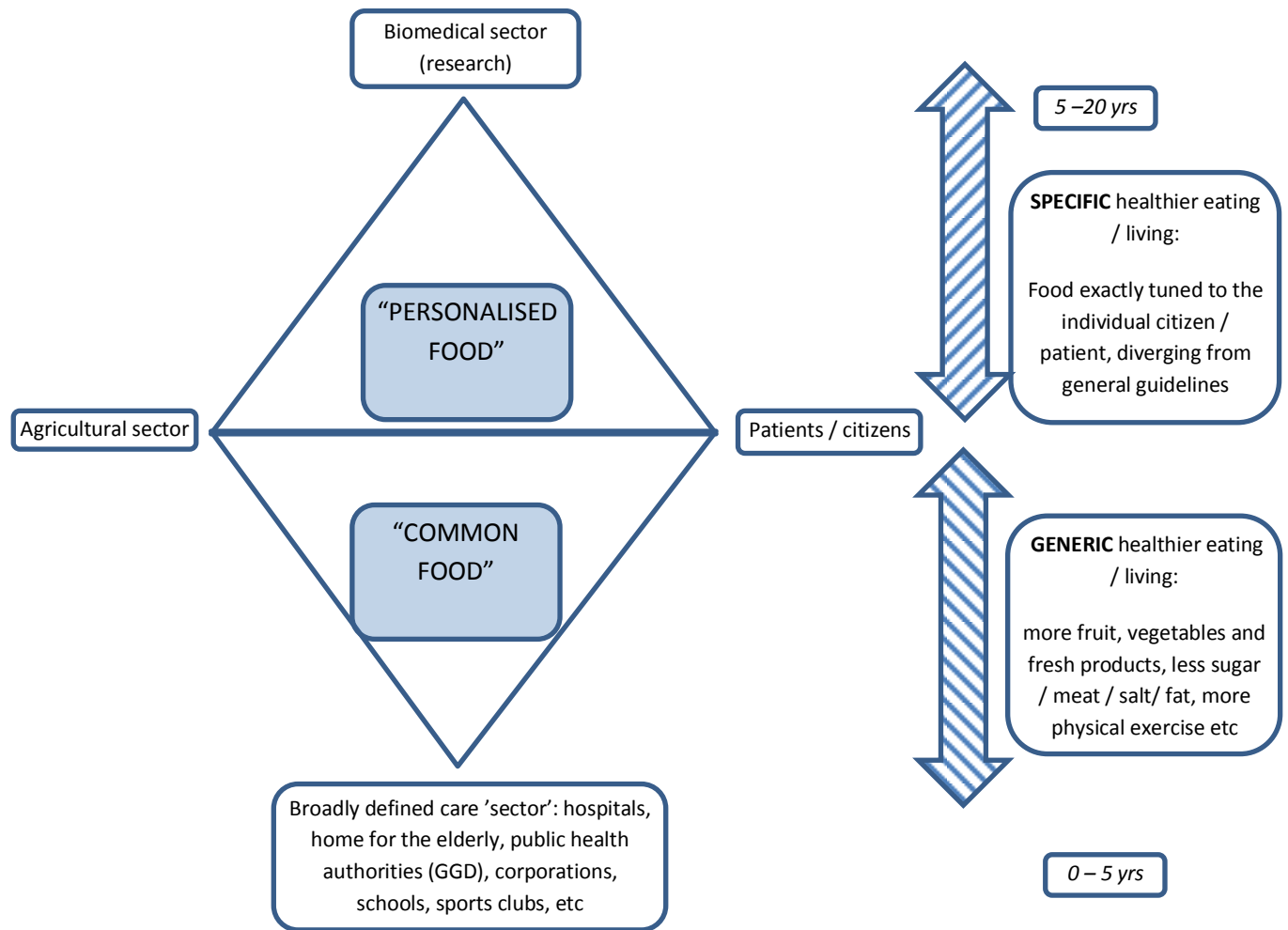
The momentum gathered in the appraisal on Personalised Food led to the establishment, in October 2014, of the Platform Patients and Food, an NGO whose mission is 'to have food acknowledged as an appropriate medical intervention and preventions strategy'. Patients with illnesses as varied as cancer, heart failure, ME, muscle dystrophy, kidney malfunctioning, lung... are members.

4. Personalised Food and Common Food

What is Personalised Food? The starting point for the Personalised Food appraisal was the assumption that every human being is different, and is likely to benefit from food that fits specifically with him or her. But what then is the 'fit'? The project defined the 'fit' as food being supportive to the health needs of an individual on a certain moment, depending on his or her constitution, condition, phase in life and life style. Everybody has a different physical and genetic basic constitution (Topol, 2014), that moreover is dynamic: hence, food needs and health goals differ. They differ in the phase of prevention of a disease, during the treatment and the period thereafter, during recovery. They differ according to the phase of life: an unborn child is in need of different food than a young kid, an adult or an elderly person (see also figure 1). Also life style has great impact: in what way does food fit with ambition of a person, and his or her socio-cultural and economic preferences.

In order to position the nature of Personalised Food better amidst the current attention for health and the role of food in it, and the many projects that are being generated in that realm, the appraisal distinguished Personalised Food from 'Common Food'. See figure 2.

Figure 2. Common Food and Personalised Food



The lower triangle establishes the playing field for Common Food, as it is at present visible in the numerous projects and coalitions around the relationship of food, food culture, food consciousness and more in general of 'green' with health and the quality of life and a healthy environment. It is carried by the currently very manifest interest in fresh food, regional products and urban green, is heralded and promoted amongst others by the urban food and urban agriculture movement and a range of civil initiatives. It becomes tangible in green gardens in homes for the elderly, fresh and regional food in hospitals, school gardens and other food awareness raising programmes at (primary) schools, sport canteens serving healthier food, housing corporations that take up a responsibility for the (green) environmental quality of their property. Businesses and health care institutions meet each other in projects like 'Better Food Better Lives', a coalition in the Dutch province of Brabant, of agricultural producers that deliver directly to health care providers. Similar initiatives also run in the Dutch province of North-Holland.

The activities in 'Common Food' are geared towards a general improvement of health via the consumption of healthier food (more vegetables, fresh food, less meat, salt, sugar, fat and fast food), based on knowledge accumulated over the past decennia and condensed in general food guidelines (like the Dutch 'Schijf van Vijf'). It has become, in a way, 'common sense'; it is, not in vain, the basis of *public health*. It concerns knowledge built through research among large population groups, generating a considerable degree of validity. The validity is, however, not complete; there are always, and sometimes considerable, deviations to the mean. The recommendations in the end go back to a statistical truth. Hence, exceptions to the rule attract attention. Why can somebody smoke during his whole life and never get lung cancer, while somebody else who does not smoke at all does? Person one can eat as much as he wants, person two grows fat eating a few cookies only. It is precisely these individual variations that generate discomfort among patients, and explain the huge popularity of the many popular food and diet books. These citizens look for a '*personalised sense of health*'. The core of Personalised Food is that it is not so much interested in statistical truth based on research among huge research populations, but instead takes the specific individual constitution and condition of a person as the point of reference. The individual DNA profile is its ultimate basis. The upper triangle hence spans the playing field for Personalised Food. Contrary to Common Food, Personalised Food lacks, at present, a lively interaction between actors, and is limited to the food industry developing functional foods, e.g. for patients that need tube feeding. There is hardly any active involvement of patients, citizens, or the primary sector. Considerable R&D effort is needed to really tune food to the individual. This concerns e.g. system-biological research on the metabolic map, that, in combination with other biomedical parameters indicative of a persons' actual condition and with knowledge in the domain of human nutrition, can provide more accurate clues as to what kind of food and what compounds a person is in need of. It also concerns agricultural and nutritional research on the sustainable development and production of crops and varieties with a specific set and amount of compounds.

Results of theoretical modeling should be tested on their validity in a live context with real persons. Corresponding business models and logistic concepts need to be developed. This holds true not only within the context of the formal health system, but also and maybe even more importantly, beyond it, as Personalised Food is in fact primarily geared towards prevention. Involvement of patient organisations from the onset seems crucial for civic support (think of ethical questions) and *license to produce*.

Both triangles need each other. Common Food legitimizes the development of Personalized Food, as it creates the cultural and civic support base. It also generates the short logistic chains, the networks and the business concepts, that can be taken further as the revenues and results of Personalised Food become clearer and more applicable. Complementary, Personalised Food provides Common Food of a new scientific knowledge base, and pulls up the generic quality of Common Food and the public awareness about it. The realization of Common Food-for-all is a goal attainable on shorter notice than PF-for-all.

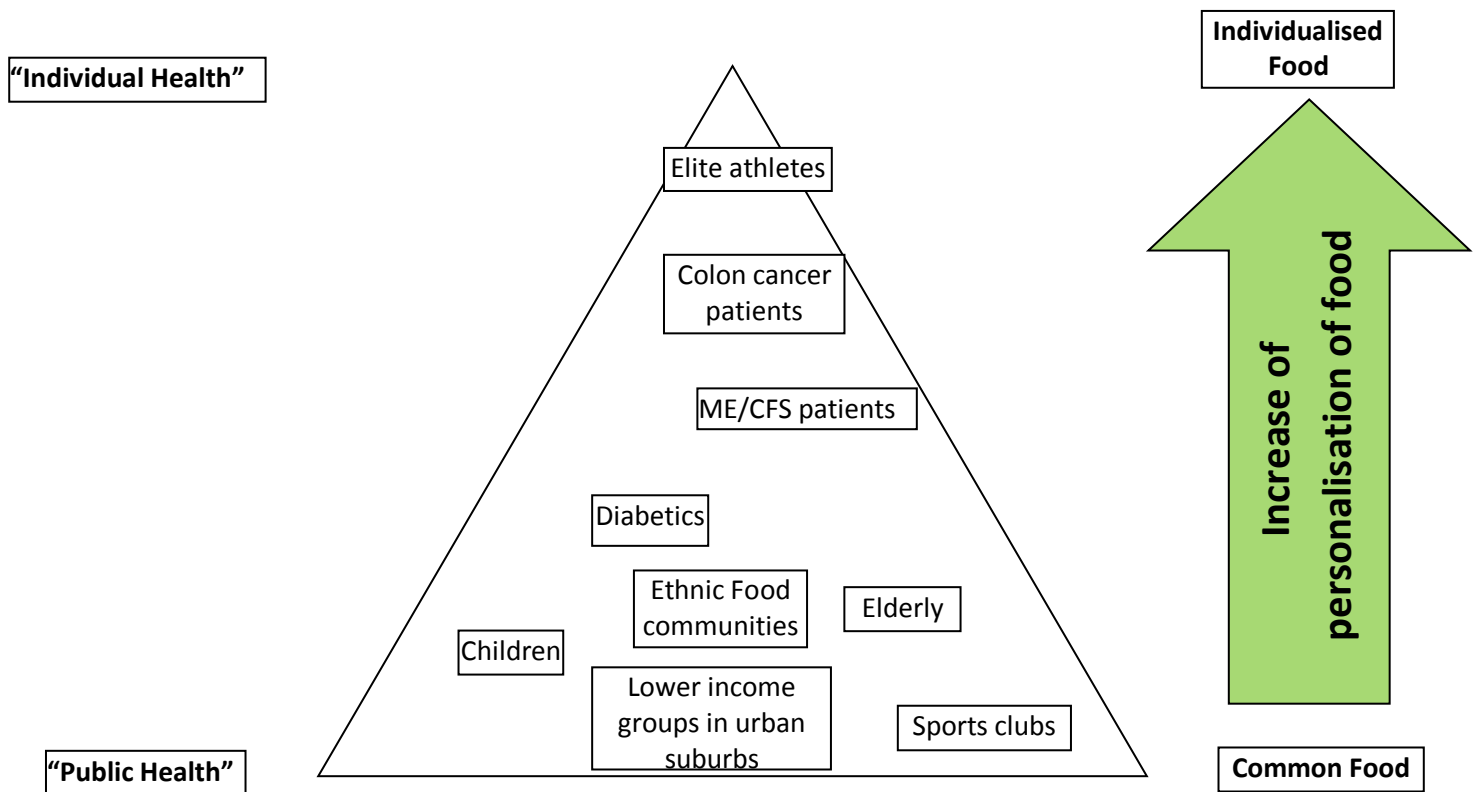
To put it even stronger: Personalised Food and Common Food are not oppositional movements, but form a continuum. The urge for a more customised approach can also be found in projects and programmes in the realm of Common Food, when it comes to addressing specific target groups, and creating a sphere and service around food that corresponds to these groups. An example is a recent project of the Dutch Foundation Food is Alive (Stichting Voeding Leeft) and InnovatieNetwerk: a group of diabetes type 2 patients develop, supported by specific biomedical support, different food routines as a key to their cure.

The use of DNA and systems biology to achieve individualised food and dietary advice can be considered as the most extreme form of Personalised Food. You could call it *Individualised Food*. The conducted appraisal took this position as a reference point. The reason is that this form of Personalised Food raises the question most clearly: does this piece of food work for **ME**? For my unique physical constitution, my DNA, my life style, my cultural background, my taste? It forces us to recognize that a human being is unique and dynamic interplay of genes and environment, and that an accurate and respectful acknowledgement of this fact may lead to a better health care system – may be also a cheaper system, as more focus is given to prevention. From this perspective the urgency and possibilities increase to create food offers for identifiable groups with more or less similar characteristics. Medicines have long been developed based on research among men, while recently it has become clear that women have a different reaction to medicine. What about food? It is also clear that cardiovascular patients need a other dietary advice than obesity patients. Socio-economically disadvantaged groups from urban suburbs need other food advice than those in the well-to-do areas. Elderly differ in their needs from children. Colon cancer patients again need different food advice than esophageal cancer patients. A hopeful project is currently being developed by the Dutch caterer Hutten in collaboration with

Wageningen University, in a project aimed at food offers for patients in nursing homes with a range of different cancer types. Maybe an ethnic component is involved too: beyond cultural preferences, e.g. ethnic Chinese might do better on other food than ethnic Dutch. It is at least absolutely clear that different segments of the population employ different ingredients in their kitchen.

Hence, between Individualised Food and Common Food there is a gradient of more customised, personalised approaches to tune food to an individual. Thus, Personalised Food based on DNA research is not an isolated, singular and deviant way of viewing food, but forms part of a repertoire of *Personalised Food Systems* (see figure 3). By framing Personalised Food in this way, we are at the same time able to bridge conceptually and policy wise Individualised and Common Food, and to go beyond an oppositional and possibly counterproductive representation of these food domains (cf Maye, 2014:387). With this perspective, very different projects and programmes on food can be envisioned and understood along an axis of increased personalization of a food system, with different supply chains, target groups etcetera. It brings together, under one umbrella, seemingly diverse and different forms of customized food networks, with a range of goals, such as food targeted at specific ethnic groups, urban gardening programmes, food literacy and educational programmes, social cohesion, citizen empowerment, spatial quality enhancement, public food procurement by hospitals and governmental bodies, sport canteen programmes etcetera. This is interesting from a biomedical perspective, and from the perspective of primary producers and the food industry – and of course from the perspective of patients and citizens. Essentially, it invites actors to address profoundly the question: who do we work for? What market, what goal, what quality?

Figure 3: Personalised Food Systems: a diversity of target groups, coalitions, networks and markets on an gradient between Common Food and Individualised Food



5. Personalised food and the challenge for the horticultural sector

The Dutch horticulture, albeit a major world exporter of food, is facing a considerable crisis. Its comparative advantages over other producing regions across the globe are becoming smaller, as (Dutch) horticultural technology is available everywhere, also in countries with lower costs of labour. Hence, since a few years the interest 'quality horticulture' (the Dutch term is 'voedingslandbouw') is emerging. 'Quality' refers in this case to organoleptic quality, but increasingly also to the amount of health supporting chemical substances. In this context, the so-called 'lycopene-tomato' was developed, containing higher levels of lycopene, with proven health effects for cardiovascular diseases and cancer (Limpens, 2004). The introduction of the lycopene tomato was not a big success, people could hardly identify with lycopene. Hence, the development of this 'quality horticulture' is rather slow.

The emergence of Personalised Food may offer new avenues for the horticultural sector. In doing so, at least two major challenges need to be faced: plantbreeding and production protocols, and marketing.

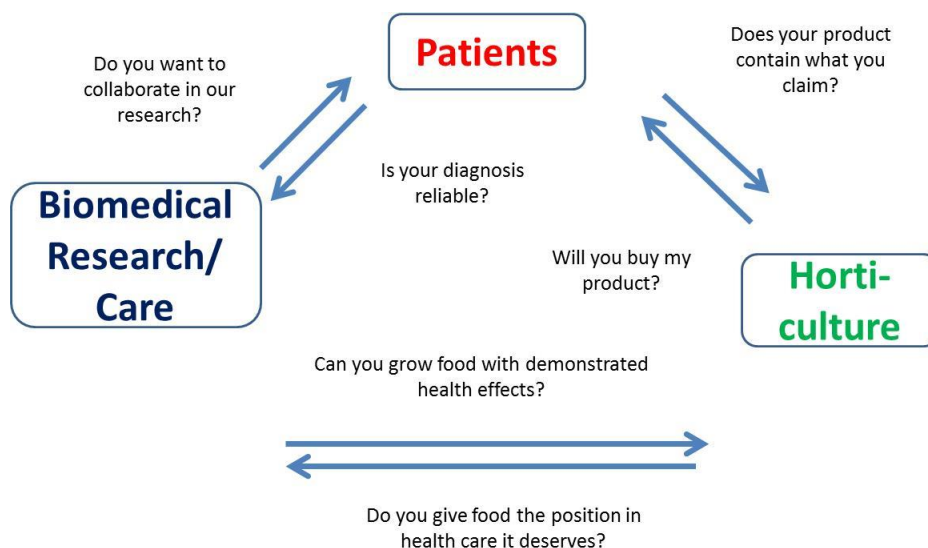
The plant production challenge of Personalised Food implies a much stronger focus on managing optimal conditions for plant growth and the optimal moment for harvesting. Plants contain up to 30.000 chemical compounds, and a substantial number of them is only assembled in specific stages of the development of the plant, or under specific conditions. It turns out that growth conditions that are usually considered to be prohibitive for optimal growth (too little light, water and fertilizers, too many plant predators etcetera), induce a plant to develop specific metabolites in order to defend itself and prosper despite the adversity. Many of these metabolites are precisely the ones that are supportive to human health. Also a natural ripening process leads to an increase of these compounds. So Personalised Food demands growers to pay a much closer look at their production conditions and timing of the harvest. It may lead to an increased focus on quality, it may inspire new definitions of 'plant vitality', and it may stimulate the development of just-in-time fresh production, beyond what is already possible now. It may hence lead to a new dimension of short supply chains; it is even thinkable that future personalised horticulture will take place in a specially equipped glasshouse that is part of a family kitchen - Urban Farming brought inside your home.

The marketing challenge implies the way health claims are handled and products are articulated with end consumers. *First*, the sector tends to focus on the possibility to market with accepted health claims. This is a very time consuming and difficult process. Health claims of food need to be validated through the European Food Safety Authority. To date, only a very limited number of products are listed with accepted health claims – leading to the paradoxical situation that a farmer may not claim his vegetables are 'healthy'. Well known is the Dutch case of Koppert Cress director Rob Baan, who was sanctioned by government while claiming the health of his broccoli sprouts. However, there is of course a logic to the reluctance to accept health claims too easily. Plant products are indeed composed of a myriad of compounds, it still is insufficiently clear what compound, or what combination of compounds are responsible for the alleged health effect, and in what kind of person. Hence, there are quite a few uncertainties to solve, both regarding plant production as well as regarding the match with the individual condition. At the same time, there are many different popular health traditions that have elaborated extensive schemes based on food, like the Ayurvedic tradition, or in Chinese Traditional Medicine (Kasteren et al, 2010). *Second*, the sector has such a tremendous production capacity that a considerable market is needed in order to make up for the investments. Producing for one patient is, at present, not an option. Hence, clear market demand is a crucial for the horticultural sector to develop 'quality food'.

The Personalised Food project suggests that co-creative Research and Development processes may serve as a way to deal with these challenges (see for a similar

argument in medical technology development Lal et al, 2012). Main stakeholders in these processes are typically patient groups, the biomedical sector and horticultural producers (see figure 4). In a co-creative process , a number of uncertainties can be turned into manageable issues. Patients will be asking if they can trust the grower, when he asserts that his products contains this and that. They will ask the biomedical sector to improve possibilities for individual assessment of health needs, that can be solved with food. Producer will want to know if consumers will buy his product. Etcetra. In a co-creative process, trust can grow beyond health claims. Personalised Food, in the end, is not a technological challenge, but a challenge to the development of trust.

Figure 4. Key stakeholders involved in formation of new co-creative business coalitions in Personalised Food, including some of the questions they deal with.



6. Concluding remarks and questions

Obviously, there is much more to be said on Personalised Food, and the development agenda is huge, both for the horticultural sector and for the biomedical sector. The key question, however, that I like to raise here is this one:

Should we continue to see patients as the weak, the helpless, as those who put a burden on society, as people who cost money and limit productivity and growth, or are we able to see patients as the ice breakers that cut through the frozen sea of the agro-food sector, and help the sector to reinvent itself as the heralds of health and wellbeing? For its own benefit and that of society?

This paper has provided some arguments that the latter point of view bears potential; the hypothesis is hence that patients movements on food potentially embody a power that can speed up the development of a more sustainable agro-food system. It brings to mind the decisive and transformational impact the HIV-AIDS movement has had in eighties and nineties of the 20th century on the development of appropriate new drugs (see e.g. the 2012 Oscar nominated documentary 'How to survive a plague'⁴).

The hypothesis also brings along a number of theoretical, practical and ethical questions that demand serious international attention from both researchers, practitioners and patient activists. Without pretending to be exhaustive, here's a kick-off to these questions:

- Is Personalised Food, empowered by patients, a vehicle for radical change, or is it likely to be appropriated by dominant market forces, leading to even more and now individualised control of food habits?
- Does the Common Food / Personalised Food framing inspire the mainstream agrosector to modify its practices?
- Does the CF/PF framing provide an alternative to the conceptualization of Alternative Food Networks, does it add a significantly new layer to it, or is it basically a refinement?
- What is the potential of Personalised Food to raise the quality and volume of e.g. public food procurement (think hospitals), the diversity of short supply chains and the quality and output of co-creative, multistakeholder R&D trajectories?
- Is Personalised Food an elitist development, available for the happy few, or is it paving and accelerating the way for lower income groups to acquire good food?
- What is the state of the art of the patients movements on food around the globe?
- What are the concerns and challenges of these movements, in order to become an power to be reckoned with?
- Are patients able to trigger alternative visions on food and health, and impact both the agrofood system and the healthcare system?
- How should we, in sum, assess the potential of Personalised Food to transform form a niche innovation to a regime change? What actions should come in place?

I would very much welcome all reflections and collaborative efforts to explore the potential of Personalised Food and the potential of patient food movements.

⁴ *How to survive a plague*, a film by Sundance Selects. <http://www.ifcfilms.com/films/how-to-survive-a-plague>.

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